

The Impact of Food Allergies on Quality of Life

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ABSTRACT

Food allergies are a growing health concern, yet scientific understanding of how individuals' lives are affected by food allergies is limited. The aims of this project were to explore the factors that affect the lives of adults with food allergies; to quantify the level of impact these factors have on daily functioning; to test the role of socio-demographic factors and personality on how food allergies are experienced; and to identify strategies to improve the quality of life of adults with food allergies. A mixed-methods approach was taken, starting with a qualitative method (Study 1), which was used to inform the development of the quantitative method (Study 2).

Study 1 explored the experiences of adults with food allergies and the implications of their experiences in terms of consumer vulnerability and impact on health-related quality of life. Focus groups were held with four groups of adults with food allergies to gain an in-depth understanding of how their food allergies affected their lives. The participants 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). Food allergy specific factors that influenced their experience of vulnerability in different contexts included food allergy type and symptom severity (individual characteristics), stage of adaptation to food allergy and level of knowledge acquired (individual states), discrimination/stigmatization, cost and availability of allergen-free food, labelling of food, and the knowledge level of café and restaurant staff (external conditions). Key factors that influenced health-related quality of life 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.

To extend this investigation, Study 2 quantified the frequency of food allergy issues in daily life and tested the impact of food allergy issues on daily functioning (i.e., experiences of stress, mood, and physical energy). Adults with food allergies ($N = 108$; 85% women; ages 18 – 87) completed an initial Internet-based survey collecting socio-demographic, personality, and food allergy information. This was followed by a 2-week Internet-based daily diary survey in which participants reported their daily experiences of stress, mood, and physical energy, followed by a 25-item checklist (based on the result of

Study 1) about the occurrence of food allergy issues during that day. Analysis of the daily surveys showed several commonly experienced allergy issues. These included negative physical symptoms of food allergy, extra financial cost due to higher food prices, feeling anxious about whether food is safe to eat, trouble with maintaining a healthy diet, and feeling anxious or stressed at social occasions involving food. Multilevel modelling analyses showed that people experienced significantly higher stress and negative mood on days with more allergy issues. Older adults also experienced reduced positive mood and physical energy on days with more allergy issues. Participants living in smaller towns and rural locations experienced more issues per day compared to participants living in cities. Personality traits were found to influence the experience of food allergies in daily life. This study corroborated and extended the findings from Study 1, showing that food allergy-related issues are a common occurrence and source of stress in daily life.

Taken together, both Study 1 and Study 2 show that adults with food allergies experience food allergy issues frequently, which has implications for their psychological, social, and physical functioning. Targeting the issues identified in this research will reduce stress in patients with food allergies and improve their overall health and quality of life.

LIST OF PUBLICATIONS ARISING FROM THIS THESIS

Journal publications

1. Peniamina, R.L., Bremer, P., Conner, T.S., & Miroso, M. (2014). Understanding the needs of food-allergic adults. *Qualitative Health Research*, 24(7): 933-945.
Impact Factor: 2.181 | Ranking: 17/67 in Health Policy & Services. Source: 2012 Journal Citation Reports® Thomson Reuters, 2013.
2. Peniamina, R., Bremer, P., Conner, T.S., Miroso, M. (2014). The food allergy journey: understanding the lived experiences of food-allergic consumers as a pathway towards improving their wellbeing. *Journal of Research for Consumers*, 25: 20-52.
(Currently there are no citation statistics available as the journal is relatively new. The editors and advisory board comprise leading scholars in the consumer research field).

Conference proceedings

1. Peniamina, R., Miroso, M., Conner, T., & Bremer, P. (2012, July). Food allergies: understanding the issues from a consumer perspective. Oral presentation and poster presented at the *Asia Pacific Association for Consumer Research Conference*, Queenstown, New Zealand. Extended abstract published in *Asia-Pacific Advances in Consumer Research*, 10, pages 69-70.
2. Peniamina, R., Miroso, M., Bremer, P. & Conner, T. (2013). Development of a measure to determine the impact of food allergies on the daily lives of food allergenic adults. Poster presented at the *European Academy of Allergy and Clinical Immunology and World Allergy Organization (EAACI & WAO) World Allergy & Asthma Congress 2013*, Milan, Italy. Abstract published in *Allergy*, 68 (suppl. 97), page 320.

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Balancing life as a mother and wife with the challenges of completing this research has not been easy. However, it has been a fulfilling and rewarding experience motivated by the knowledge that my hard work may one day contribute to helping others with food allergies. During the past three and a half years, many people have contributed to the successful completion of my PhD.

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TABLE OF CONTENTS

Abstract	ii
List of publications arising from this thesis	iv
Acknowledgements	v
List of figures	xii
List of tables	xiii
Chapter 1. Introduction	1
1.1 Overview	1
1.2 Contributions of this thesis	3
1.3 Thesis style and layout	3
1.4 Definition of key terms	5
1.4.1 Food allergy	5
1.4.2 Quality of life and health-related quality of life.	5
1.4.3 Big Five personality traits	6
1.4.3.1 Neuroticism	6
1.4.3.2 Openness	6
1.4.3.3 Extraversion	6
1.4.3.4 Agreeableness	6
1.4.3.5 Conscientiousness	6
1.5 Aims and objectives	7
Chapter 2. Review of literature	8
2.1 Background	8
2.1.1 Food allergies	8
2.1.1.1 Definition of food allergy and hypersensitivity	8
2.1.1.2 Types of foods causing allergic reactions	10
2.1.1.3 Symptoms of food allergies	13
2.1.1.4 Prevalence of food allergies	15
2.1.1.5 Summary	19
2.1.2 Quality of life research	20

2.1.2.1	What is quality of life?.....	21
2.1.2.2	Quality of life and consumer research	21
2.1.2.3	Quality of life in the health sector.....	22
2.1.2.4	Research methods in health-related quality of life research	23
2.1.2.5	Summary	30
2.1.3	Mixed methods research	31
2.1.3.1	Theoretical underpinnings of mixed methods research	31
2.1.3.2	Mixed methods research design	31
2.1.3.3	Mixed methods in the current research	33
2.2	Food allergies and quality of life	33
2.2.1	Children/adolescents with food allergies and their parents	34
2.2.2	Adults with food allergies.....	37
2.2.3	Food allergy issues	40
2.2.3.1	Issues related to finding safe foods	40
2.2.3.2	Issues related to participation in social activities.....	41
2.2.3.3	Issues related to medical care	42
2.2.3.4	Costs of having a food allergy	42
2.2.3.5	Psychological/emotional issues	43
2.2.3.6	Food allergy issues and stress	43
2.2.4	Limitations of available quality of life literature	44
2.2.4.1	Limitations of food allergy research in New Zealand	45
2.3	Conclusion	46
Chapter 3. Study 1: Understanding life with food allergies		47
3.1	Introduction.....	47
3.1.1	Overview of Study 1	47
3.1.2	Background information	47
3.1.2.1	Consumer vulnerability.....	48
3.1.2.2	Health-related quality of life	49
3.2	Methods.....	51
3.2.1	Methodological approach	51

3.2.2	Study design and recruitment	51
3.2.3	Participants	52
3.2.4	Ethics	54
3.2.5	Data collection	54
3.2.6	Data analysis	57
3.3	Findings.....	59
3.3.1	Consumer vulnerability perspective	59
3.3.1.1	The journey to diagnosis	63
3.3.1.2	Reaction to diagnosis	65
3.3.1.3	Adjustment to a new life	66
3.3.1.4	Ongoing life with food allergies	67
3.3.1.4.1	Having food allergies has shaped my life path.....	68
3.3.1.4.2	Having food allergies restricts my life	68
3.3.1.5	Understanding the experience of symptoms	72
3.3.2	Health-related quality of life perspective	74
3.3.2.1	Issues related to living with a food allergy	74
3.3.2.1.1	Allergen-free eating issues.	74
3.3.2.1.2	Health care system issues.	78
3.3.2.1.3	Costs of having a food allergy.....	79
3.3.2.1.4	Effects on well-being.....	80
3.3.2.2	Factors that influence the perceived impact of food allergy and ability to cope.....	82
3.3.2.2.1	External influences.	82
3.3.2.2.2	Internal influences.	84
3.4	Discussion	85
3.4.1	Consumer vulnerability	85
3.4.2	Health-related quality of life.....	87
3.4.3	Strengths and limitations	93
3.5	Conclusion	94

Chapter 4. Study 2: The stress of food allergy issues in daily life	96
4.1 Introduction.....	96
4.1.1 Overview of Study 2.....	96
4.1.2 Background information.....	97
4.2 Method.....	100
4.2.1 Study design.....	100
4.2.2 Participant recruitment.....	100
4.2.3 Measures.....	101
4.2.4 Data collection.....	103
4.2.5 Statistical analysis.....	104
4.3 Results.....	105
4.3.1 Participants.....	105
4.3.2 Frequency and type of allergy issues.....	108
4.3.3 Food allergy issues and daily functioning.....	110
4.3.3.1 Between-person analyses.....	110
4.3.3.2 Within-person analyses.....	110
4.3.4 Factors influencing the frequency and type of food allergy issues.....	111
4.3.5 Influence of personality.....	112
4.3.5.1 Neuroticism.....	113
4.3.5.2 Openness.....	113
4.3.5.3 Extraversion.....	113
4.3.5.4 Agreeableness.....	114
4.3.5.5 Conscientiousness.....	114
4.4 Discussion.....	114
4.4.1 Strengths and limitations.....	118
4.5 Conclusion.....	120
Chapter 5. General discussion and conclusions	121
5.1 Introduction.....	121
5.2 Summary of key findings.....	121
5.3 Implications and contributions of the thesis.....	126

5.3.1	Implications in the context of Self-Efficacy Theory	126
5.3.2	Implications in the context of the Theory of Reasoned Action	127
5.3.3	Theoretical	129
5.3.4	Methodological	129
5.3.5	Clinical.....	130
5.3.6	Policy	130
5.3.7	Food Industry.....	131
5.3.8	Advocacy	132
5.4	Limitations	132
5.5	Conclusions.....	133
5.6	Future research.....	133
5.7	Concluding statement.....	134
	References.....	136
	Appendices	153

LIST OF FIGURES

Figure 1.1 Overview of research presented in this thesis	2
Figure 2.1 Nomenclature for food hypersensitivity.....	10
Figure 3.1 Introductory exercise with ten statements about living with food allergies.....	55
Figure 3.2 Overview of key themes and how they interrelate	75

LIST OF TABLES

Table 2.1 Overview of common allergens and associated symptoms/disorders	12
Table 2.2 Challenges or limitations in relation to determining the prevalence of food allergies.....	16
Table 2.3 Estimated allergy prevalence rates for common food allergens.....	20
Table 2.4 Overview of common qualitative and quantitative research methods used for health-related quality of life research	24
Table 3.1 Summary of study participants' food allergy details.....	53
Table 3.2 Steps followed in thematic analysis	58
Table 3.3 Characteristics of focus group participants	60
Table 4.1 Socio-demographic information of the study participants	106
Table 4.2 Food allergy information of the study participants	107
Table 4.3 Proportion of participants affected, frequency reported, perceived stress experienced, and perceived impact on daily tasks for top ten issues	109
Table 5.1 Summary of key findings from this thesis.....	121

CHAPTER 1

INTRODUCTION

1.1 Overview

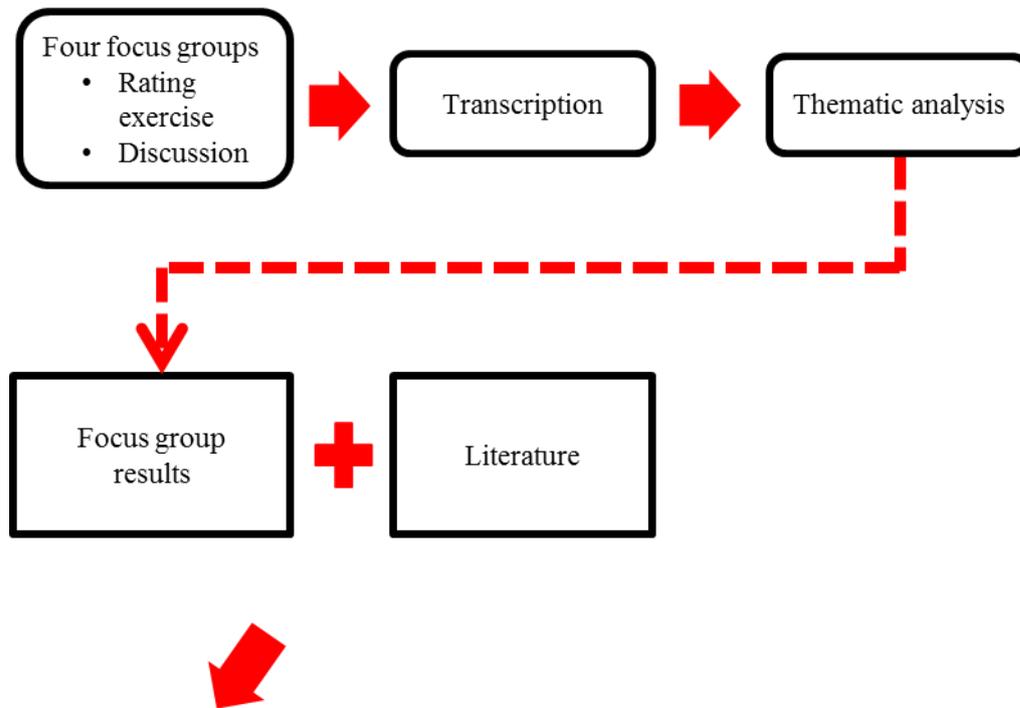
Imagine going out for lunch with a group of friends but the café you go to is unable to provide you a meal; walking down the aisles of a supermarket in despair because you cannot find food that is safe for you to eat; or having to pay double or even triple the normal price of food items. How would you deal with that? These are some of the issues that individuals with food allergies face. Food allergy is a chronic health condition that differs from many other chronic conditions because many of the issues that arise are not related to the experience of symptoms. The focus of this thesis is on understanding these issues and how they affect the physical and psychological well-being of individuals with food allergies.

Food allergy is an interdisciplinary research area that has attracted interest from medical researchers, psychologists, and food industry/food service researchers. This has led to segmentation of the research, with many publications being focused on very specific aspects of the problem rather than presenting the whole picture. The research described in this thesis is the result of an interdisciplinary, mixed methods approach to the overall research question: “How do food allergies impact on the quality of life of food allergic adults?”

An inductive approach with a largely interpretivist perspective was used to allow for novel findings in terms of what the issues are, as well as the development of a better understanding of how and why the lives of individuals with food allergies are affected (Study 1). However, the study design also incorporated a pragmatic viewpoint by acknowledging that the best possible outcome, in terms of knowledge produced, would be achieved by combining methods that are typically associated with different philosophical positions. The resulting mixed methods research employed a qualitative method (focus groups) for the exploratory stages to gain a detailed understanding of what issues adults with food allergies face, how these issues affect them, and why. This was followed by a quantitative method (daily surveys) to enhance the level of knowledge produced with data

on the frequency and level of impact of food allergy issues in daily life. A diagrammatical overview of this research is presented in Figure 1.1.

Study 1 (Qualitative)



Study 2 (Quantitative)

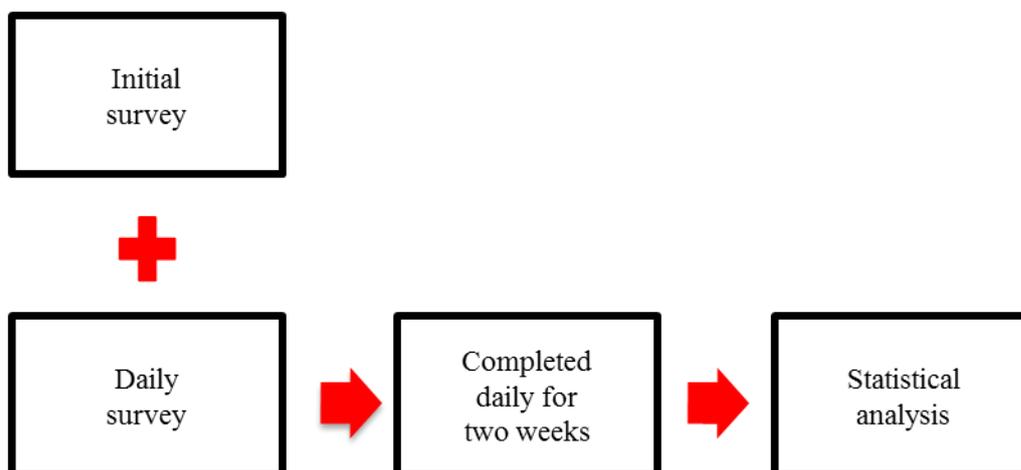


Figure 1.1 Overview of research presented in this thesis

Focus groups were used to generate the data in Study 1 because they enabled in-depth discussion of both similar and contrasting perspectives among diverse groups of

adults with food allergies. The data provided by the daily survey method used in Study 2 not only included information about the experiences of different participants, but also the different experiences of individuals on a number of different days. Statistical analysis using hierarchical linear modelling (HLM) software allowed for within-person analyses, where relationships between the number of food allergy issues reported and experiences of daily stress, mood, and physical energy could be calculated for individual participants using their daily data.

1.2 Contributions of this thesis

A detailed discussion of the contributions of this thesis is included in Chapter 5. In summary, this thesis contributes to an improved overall understanding of what life is like for adults with food allergies. The results of Study 1 provide an insight into the experiences, views, and behaviours of adults with food allergies. The range of participants from different backgrounds and with different types of food allergies included in Study 1 made it possible to access a wider range of experiences and viewpoints. The use of a real-time data collection method (daily surveys) in Study 2 is new in the food allergy research field. This is the first study to examine the frequency of food allergy issues and the implications for daily psychological functioning (stress and mood). In addition, Study 2 identified issues that are important based on the proportion of participants affected, the frequency of reporting, and the level of reported impact. Interventions targeting the top issues identified by this research are therefore likely to reduce stress and improve quality of life for adults with food allergies.

1.3 Thesis style and layout

This thesis consists of five chapters, including the current introductory chapter which gives an overview of the research approach and thesis style. Chapter 2 presents background information to aid the understanding of the topic area, followed by a critical review of relevant literature in the area of food allergies and quality of life. Limitations of the available literature are discussed and a need for more quality information about the experiences and needs of adults with food allergies is identified.

Chapter 3 presents Study 1, a qualitative study designed to address the gap in information about the experiences and needs of adults with food allergies. Two manuscripts based on Study 1 have been published, as follows:

1. Peniamina, R.L., Bremer, P., Conner, T.S., & Miroso, M. (2014). Understanding the needs of food-allergic adults. *Qualitative Health Research, 24*(7): 933-945.
2. Peniamina, R., Bremer, P., Conner, T.S., Miroso, M. (2014). The food allergy journey: understanding the lived experiences of food-allergic consumers as a pathway towards improving their wellbeing. *Journal of Research for Consumers, 25*: 20-52.

The Qualitative Health Research manuscript presents the data with a health-related quality of life focus, while the Journal of Research for Consumers manuscript presents the data with a focus on consumer vulnerability. Chapter 3 is a blend of these two manuscripts. The research is therefore presented in a format that is appropriate for these journals (and is mandatory for manuscripts submitted to Qualitative Health Research). The writing style is in first person with a preference for active rather than passive voice. This contrasts with the writing style used throughout the other thesis chapters, which are written in third person. The difference in writing style between chapters was believed to be appropriate because of the interdisciplinary nature of this thesis.

Chapter 4 presents Study 2, a quantitative study designed to determine the frequency and impact of food allergy issues in daily life. This research addressed the identified gap in quantitative data needed to substantiate the necessity of policy changes suggested based on the findings in Study 1. Chapter 4 is an extension of a manuscript that has been submitted to the Journal of Health Psychology and is currently under review. A poster detailing the development of the daily survey used in Study 2 (which was based on the results of Study 1) was presented at the European Academy of Allergy and Clinical Immunology and World Allergy Organization (EAACI & WAO) World Allergy & Asthma Congress 2013 in Milan, Italy. The abstract is published in a supplementary issue of Allergy, as follows:

Peniamina, R., Miroso, M., Bremer, P. & Conner, T. (2013). Development of a measure to determine the impact of food allergies on the daily lives of food allergenic adults. Poster presentation at the *European Academy of Allergy and Clinical Immunology and World Allergy Organization (EAACI & WAO) World Allergy & Asthma Congress 2013*, Milan, Italy. Abstract published in *Allergy*, 68 (suppl. 97), page 320.

Chapter 5 presents a discussion of the implications and contributions of the findings presented in this thesis, along with limitations, overall conclusions, and directions for future research.

1.4 Definition of key terms

The definitions of key terms used in this thesis are described in this section. These definitions describe how these terms should be understood in the context of this thesis.

1.4.1 Food allergy

A discussion of how food allergy is defined by different sub-groups of the population is included in Chapter 2. For the purpose of this thesis, food allergy was defined 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., coeliac disease).

1.4.2 Quality of life and health-related quality of life.

A discussion of what the terms quality of life and health-related quality of life represent is included in Chapter 2. For the purpose of this thesis, quality of life was defined as the physical, emotional, social, and financial well-being of an individual and

health-related quality of life was defined as the patient-perceived functional impact of their food allergy and its management on the patient's quality of life.

1.4.3 Big Five personality traits

The Big Five Inventory 44 item personality test (BFI-44) used in this research measures neuroticism, openness, extraversion, agreeableness, and conscientiousness traits. Definitions for these personality traits were sourced from John, Naumann et al. (2008).

1.4.3.1 Neuroticism

“Neuroticism contrasts emotional stability and even-temperedness with negative emotionality, such a feeling anxious, nervous, sad, and tense.”

1.4.3.2 Openness

Openness refers to openness to experience (as opposed to closed-mindedness) and “describes the breadth, depth, originality, and complexity of an individual's mental and experiential life.”

1.4.3.3 Extraversion

“Extraversion implies an energetic approach toward the social and material world and includes traits such as sociability, activity, assertiveness, and positive emotionality.”

1.4.3.4 Agreeableness

Agreeableness refers to a pro-social and more communal orientation toward others and is associated with increased modesty, trust, altruism, and tender-mindedness.

1.4.3.5 Conscientiousness

“Conscientiousness describes socially prescribed impulse control that facilitates task- and goal-directed behaviour, such as thinking before acting, delaying gratification, following norms and rules, and planning, organizing, and prioritizing tasks.”

1.5 Aims and objectives

- To explore the factors that impact on the quality of life of adults (18+) with food allergies.
- To quantify the frequency of the different factors identified and their level of impact on the quality of life of adults with food allergies on a daily basis.
- To explore the influence of socio-demographic factors and personality on how food allergies are experienced.
- To identify strategies to improve the quality of life of adults with food allergies.

Research question:

How do food allergies impact on the quality of life of adults with food allergies?

CHAPTER 2

REVIEW OF LITERATURE

2.1 Background

This chapter presents relevant background information on food allergies and quality of life research methods, followed by a critical review of current literature related to the quality of life of individuals with food allergies. The background information on food allergies is included to aid the understanding of this thesis in terms of what food allergies are and the importance of food allergies for public health. The overview of quality of life and methods for researching quality of life is included to clarify the position of this thesis and provide a background understanding of advantages and limitations of methods used for quality of life research. The critical review incorporates a discussion of the available literature related to food allergies and quality of life and the limitations of current knowledge in this area.

2.1.1 Food allergies

Knowledge of how food allergy is defined, the symptoms that food allergy can cause, and how many people are affected is important to the understanding of this thesis. This section presents a discussion of how food allergy is defined by medical professionals and the general public, concluding with a statement of the food allergy definition used for this thesis. The types of foods causing allergic reactions, symptoms of food allergy, and current knowledge about the prevalence of food allergies are also discussed.

2.1.1.1 Definition of food allergy and hypersensitivity

The term food allergy can mean different things to different people. Although food allergy is described as an adverse immune reaction to food, medical professionals often only use the term food allergy (or “true food allergy”) in reference to Immunoglobulin E (IgE)-mediated immune responses to foods. The term food intolerance is then used to describe all other adverse reactions to foods. This is likely due to limited knowledge in the area of non-IgE-mediated immune reactions to foods. The

mechanisms of non-IgE-mediated food allergy are currently not as well understood as IgE-mediated food allergy (Morita, Nomura et al. 2013, Skypala and Venter 2009). However, as described by Metcalfe, Sampson et al. (2008), both IgE- and non-IgE-mediated food allergies have an immunological basis. A detailed description of the mechanisms of IgE-mediated food allergy can be found in Skypala and Venter (2009). In summary, IgE-mediated food allergy involves Th2 cells stimulating the production of food-specific IgE antibodies that attach themselves to cells (mainly mast cells) and remain in the tissues, a process referred to as sensitization. If the person is exposed to the allergen again, these specific IgE antibodies bind with the allergen proteins, resulting in degranulation of the cells and subsequent release of substances that cause inflammation. The resulting inflammation causes what the allergic individual experiences as symptoms. There is a tendency for members of the general public to use food allergy to describe any consistent adverse reaction to foods, which may partially explain differences between the prevalence of self-reported food allergies and food allergies confirmed by diagnostic testing (Sicherer 2011). The results of a cross-sectional survey on food allergy knowledge found that more than half of the participants thought lactose intolerance was the same as milk allergy (Gupta, Kim et al. 2009). These differences in the use of the term “food allergy” can cause confusion among both the general public and health professionals.

In 2001, the nomenclature for allergy was revised by a taskforce of the European Academy of Allergy and Clinical Immunology, including revised nomenclature of adverse reactions to foods (Johansson, Hourihane et al. 2001). The new nomenclature for adverse reactions to foods was also adopted by the World Health Organisation (WHO) in 2003 (World Health Organisation International Food Safety Authorities Network (INFOSAN) 2006). As outlined in Figure 2.1, ‘food hypersensitivity’ is the umbrella term incorporating both immune-mediated and non-immune-mediated adverse reactions to foods. ‘Food allergy’ has been redefined to include all immune-mediated reactions. The term food intolerance has been replaced with ‘non-allergic food hypersensitivity’, including conditions such as lactose intolerance, and hypersensitivity to sulphites. Despite the official endorsement of the new definition for food allergy by the WHO, published research on food allergy prevalence still reflects a tendency to focus on IgE-mediated food allergies (Liu, Jaramillo et al. 2010, Osterballe, Hansen et al. 2005). This is discussed in more detail in section 2.1.1.4.

For the purposes of the research described in this thesis, food allergy is defined in line with the new nomenclature as:

A reproducible adverse reaction due to an immune-mediated response to a food or food component.

This definition for food allergy allows the inclusion of common disorders involving non-IgE-mediated immune mechanisms (e.g., coeliac disease, dermatitis herpetiformis, food protein enterocolitis, and food protein-induced enteropathy or proctocolitis) under the ‘food allergy’ umbrella.

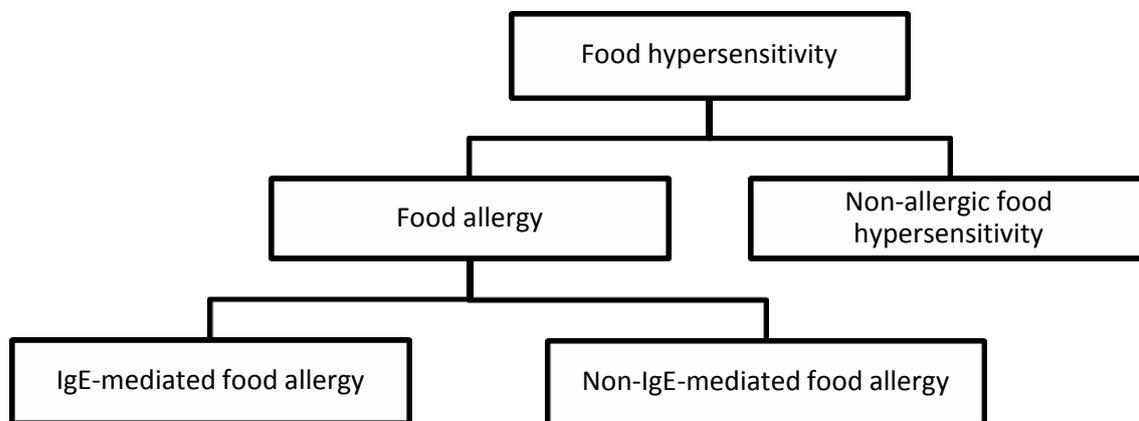


Figure 2.1 Nomenclature for food hypersensitivity (Johansson, Hourihane et al. 2001)

2.1.1.2 Types of foods causing allergic reactions

Any food can trigger an allergic response, however, only a small number of food types are responsible for the majority of food allergies. For example, the main allergens of significance in the United States of America (USA) are egg, cow’s milk, peanut, tree nuts, fish, shellfish, wheat, and soy (Sicherer 2011). The overall rate of food allergy, the main types of foods implicated, and their relative importance have been found to vary geographically (Skypala and Venter 2009, Sicherer 2011). In Europe, sesame seeds, celery, mustard, soy, and lupin are considered important as well as the main allergens listed previously for the USA (Venter and Meyer 2010); in Asia, beef appears to be an additional important allergen that is not mentioned for the other regions (Leung, Yung et al. 2009, Hon, Chan et al. 2011); and an allergy to ant’s egg was commonly reported in Thai children (Lao-araya and Trakultivakorn 2011). Comparisons in prevalence of

shellfish, peanut, and tree nut allergies between Asian and European populations showed a higher prevalence of shellfish allergy among those of Asian ethnicity (both those born in Asia and those born in Western countries) compared to those of European ethnicity (Shek, Cabrera-Morales et al. 2010). Indian and Malay participants appeared to have a higher prevalence (Malay: higher prevalence of shellfish and peanut allergies; Indian: higher prevalence of tree nut allergy) compared to other Asian ethnicities. Interestingly, both Asian and European participants born in Western countries showed a significantly higher prevalence of peanut and tree nut allergies compared to those born in Asia, suggesting country of birth (rather than ethnicity) is a significant factor in the development of nut allergies (Shek, Cabrera-Morales et al. 2010). However, while the number of Asian-born Asian participants included in the study was high ($n > 20,000$), the number of participant in the other groups was much lower ($n = 123 - 356$). This may have introduced bias in the prevalence results resulting in an invalid comparison.

Gluten is an important allergen that is often considered separately, particularly in earlier research. This is because reactions to gluten do not involve an IgE-mediated immune response and therefore fall outside of the traditional definition for food allergy (see Section 2.1.1.1). Coeliac disease is the result of a non-IgE immune response to ingested gluten. Until recently, the term coeliac disease was used interchangeably with ‘gluten-sensitive enteropathy’ and it was thought that this was the only manifestation of the disease. There is now evidence of manifestations involving other organs, such as the skin (dermatitis herpetiformis), and the nervous system (gluten ataxia, gluten neuropathy) which can appear in combination with or independently from intestinal involvement (Hadjivassiliou, Williamson et al. 2004, Hadjivassiliou, Sanders et al. 2010, Troncone and Jabri 2011). Research has shown gluten-sensitive enteropathy (the intestinal manifestation) to be both a global health problem (affecting Western and Eastern populations) and a common disorder (affecting around 1% of the population in Western countries) (Metcalf, Sampson et al. 2008).

Table 2.1 Overview of common allergens and associated symptoms/disorders

Mechanism	Common allergens	Associated symptoms/disorders
IgE-mediated (Rapid onset, usually within minutes to 2 hours)	Peanut, tree nuts, fish, shellfish, milk, egg, soy, & wheat	<p>Skin: urticaria (rash), angioedema (swelling).</p> <p>Respiratory: rhinoconjunctivitis (red, itchy eyes, nasal irritation, sneezing), laryngospasm (shortness of breath), wheezing/bronchospasm (difficulty breathing).</p> <p>Gastrointestinal: nausea, abdominal pain/cramping, vomiting and/or diarrhoea. Gastrointestinal anaphylaxis: severe immediate gastrointestinal symptoms.</p> <p>Multi-system: generalized anaphylaxis (combination of symptoms affecting multiple organ systems), food and exercise induced anaphylaxis.</p>
	Fresh fruit & vegetables	Oral allergy syndrome: rapid onset pruritus (itching) and angioedema (swelling) of the lips, tongue, palate, and throat.
Combined IgE- & non-IgE-mediated	Milk, egg, soy, wheat, peanut, tree nuts, fish, & shellfish	<p>Skin: atopic dermatitis/eczema</p> <p>Gastrointestinal: implicated in disorders involving symptoms such as vomiting, diarrhoea, abdominal pain, and malabsorption.</p>
Non-IgE-mediated (Onset within hours or days)	Milk, soy, egg, wheat	Gastrointestinal: food protein-induced enterocolitis (severe vomiting & diarrhoea), food protein-induced enteropathy (diarrhoea, vomiting, malabsorption), and food protein-induced proctocolitis (gastrointestinal lesions, bloody stools).
	Fish, shellfish, meat, egg	Skin: contact dermatitis
	Milk	Heiner's syndrome (rare syndrome in infants; symptoms include: recurrent pneumonia, gastrointestinal blood loss, failure to thrive)
	Gluten	Dermatitis herpetiformis (chronic blistering skin rash); coeliac disease (common symptoms: diarrhoea, weight loss/failure to thrive, bloating, flatulence, multiple nutrient deficiencies)

2.1.1.3 Symptoms of food allergies

The types of symptoms experienced can be divided into a number of different categories based on the body system involved. Symptoms of food allergy usually affect the skin, respiratory tract, gastrointestinal tract, or can be systemic (i.e., affect multiple organ systems) (see Table 2.1). Individual allergens may cause adverse reactions via IgE-mediated mechanisms, non-IgE-mediated mechanisms, or a combination of both. Table 2.1 outlines the allergens usually associated with the different mechanisms and the symptoms/disorders that commonly result (summarized from Metcalfe, Sampson et al. 2008). The severity of symptoms can differ between different people as well as within the same person. For example, someone may initially experience only mild symptoms but the symptoms can increase in severity at each exposure to the food. Symptoms can also subside and eventually resolve (e.g., young children may ‘outgrow’ their allergy), however this is generally not the case in adults.

The most severe form of food allergy results in anaphylaxis, which is defined as “a severe, potentially fatal, systemic-allergic reaction that occurs suddenly after contact with an allergy-causing substance” (Metcalfe, Sampson et al. 2008, p. 103). Anaphylaxis due to food allergy generally involves multiple organ systems, often including severe respiratory and cardiovascular symptoms. The foods most commonly implicated as the cause for anaphylaxis are peanuts, tree nuts, shellfish, milk, and eggs. Food-induced anaphylaxis accounts for approximately 30% of anaphylaxis cases presenting to hospital emergency departments (Liew, Williamson et al. 2009, Sicherer 2011). Liew, Williamson et al. (2009) also reported an increase in cases of anaphylaxis in Australia over a period of 9 years, but no increase in the number of fatalities. A study of children presenting with anaphylaxis to a hospital in Melbourne, Australia found food was responsible for 85% of the reactions, including one resulting in death (de Silva, Mehr et al. 2008). This data suggests an increasing burden on hospital emergency departments from anaphylaxis cases. In addition, it appears that food is more commonly implicated as the cause for anaphylaxis in children, compared with adults.

Limited information is available about the number of fatalities from food-induced anaphylaxis, with large differences between the findings of different studies. For example, a retrospective study that examined medical examiner records covering a period of two years in Maryland (USA) found 35% (6 out of 17) of anaphylaxis fatalities were attributed to a food-induced reaction (Shen, Li et al. 2009). In contrast, an Australian

study that examined records on anaphylaxis deaths and hospital admissions over a period of nine years indicated 6% (7 out of 112) of anaphylaxis fatalities were food induced (Liew, Williamson et al. 2009). A review of autopsy cases in New Zealand (Auckland Hospital) over a 20 year period found 11% (2 out of 18) of anaphylactic fatalities were food-induced (Low and Stables 2006). Based on the available statistics related to anaphylaxis cases and fatalities at hospitals, improved diagnosis, awareness, and management of food allergies is likely to reduce the burden on hospital emergency departments and reduce fatalities in addition to improving quality of life for affected individuals.

Another potentially life-threatening reaction, known as food and exercise-induced anaphylaxis, can occur when ingestion of certain foods is combined with exercise within a 2-4 hour time interval (Metcalf, Sampson et al. 2008). In this condition, the causative food/s can be eaten without problems in the absence of exercise, and exercise without eating the causative food/s does not incur symptoms, only the combination of the two factors results in a reaction (Metcalf, Sampson et al. 2008). Further, a life-threatening form of coeliac disease that requires emergency hospital treatment can also occur. This is more common in children than in adults and presents with symptoms such as profuse, acute diarrhoea, dehydration, hypokalaemia (decreased potassium in the blood), and severe metabolic acidosis (too much acid in the body fluids) (Metcalf, Sampson et al. 2008).

Food allergy has been implicated as an important trigger for eczema, particularly in those with moderate to severe eczema and can also cause or trigger asthma symptoms in some individuals (Skypala and Venter 2009). The link between asthma and food allergy was also noted by Liu, Jaramillo et al. (2010) who showed an increase in prevalence of food sensitization in those with asthma (particularly those with asthma that had resulted in a recent Emergency Department visit) compared with those without asthma. This indicates that food allergy and asthma are a potentially dangerous combination as allergic reactions to food may trigger or worsen asthma attacks. As a result, co-morbidity of food allergy and asthma may result in a higher impact on quality of life. While not life-threatening, eczema has been shown to have a significant impact on quality of life (Finlay 1996, Lewis-jones 2006, Moberg, Alderling et al. 2009). The link between asthma, eczema, and food allergies is particularly important in the context of the New Zealand population because asthma and eczema affect a large proportion of New

Zealanders. Asthma affects 20-30% of children and adolescents in New Zealand (Ellison-Loschmann, Pattemore et al. 2009) and around 15% of New Zealand adults (Lewis, Hales et al. 1997). Atopic eczema (eczema triggered by allergy) affects around 15% of New Zealand children (Asher, Barry et al. 2001).

2.1.1.4 Prevalence of food allergies

Food allergies are a growing concern in the public health domain. There appears to be an increase in prevalence of food allergies over the past ten years along with a higher incidence of emergency department visits and hospital admissions for food-induced anaphylaxis (Sampson 2014). A meta-analysis study published by Rona, Keil et al. (2007) shows that many studies have attempted to determine the prevalence of food allergies. As a result, there is considerable data available on the prevalence of food allergies, but the variation in inclusion criteria, methods used to confirm food allergy, and study population characteristics make it difficult to compare studies. Based on a review of prevalence studies, IgE-mediated food allergies (reactions involving IgE antibodies) are estimated to affect 2 – 10% of the global population (Sicherer 2011). Less is known about the prevalence of non-IgE-mediated food allergies (immune reactions that do not involve IgE antibodies) (Jyonouchi 2012), apart from coeliac disease. For this reason, the exact prevalence of food allergies is not known.

In a recent review on the epidemiology of food allergy, Sicherer (2011) identified a number of challenges affecting the determination of food allergy prevalence. These challenges also make it difficult to determine whether food allergy prevalence has increased or if there is simply an increase in awareness and reporting of food allergy symptoms. Table 2.2 summarizes some of the challenges or limitations in relation to published food allergy prevalence studies (adapted from a table published by Sicherer 2011). Some of these challenges are discussed in more detail in the paragraphs that follow.

The different food allergy definitions used by researchers have contributed to differences in prevalence data, which makes it difficult to determine the exact prevalence of food allergies. Prior to the adoption of the new nomenclature by the World Health Organization in 2003, the majority of studies defined food allergy as an IgE-mediated adverse reaction to a food. Since 2003, many (but not all) researchers appear to be aware of the new official definition for food allergy, however, the methods used for diagnosis in

many prevalence studies mean that often only IgE-mediated food allergy is being measured. For example, Liu, Jaramillo et al. (2010) made estimates of food allergy prevalence based only on serum Ig-E levels for specific foods (peanut, milk, egg, shrimp), which will have resulted in underestimating the true prevalence of food allergies as IgE-mediated reactions to other foods and non-IgE-mediated food allergies were not included. Osterballe, Hansen et al. (2005) only defined a reaction as allergic food hypersensitivity if subjects had at least one positive test result, combined with a positive open food challenge. However, diagnostic laboratory tests performed by Osterballe, Hansen et al. (2005) were all specific tests for IgE-mediated food allergy, thus excluding those with non-IgE-mediated food allergies from this group.

Table 2.2 Challenges or limitations in relation to determining the prevalence of food allergies (adapted from Sicherer 2011)

Challenge/limitation	Considerations
Definition of food allergy	Differences in inclusion criteria e.g., IgE immune responses only vs all immune responses vs outcome of oral food challenge (immune mechanism not proven) vs self-reported (reaction not clinically proven).
Food/s targeted	Prevalence studies often test only for a limited number of foods.
Method of diagnosis	Variation in interpretation of tests and type of testing used will influence the results.
Participation	Possible participation bias to include those more likely to be affected; Participants with more severe reactions more likely to drop out if oral food challenge is included in procedures.
Timing/frequency of evaluations	Allergy may develop or resolve (particularly in children) during course of study.
Data analysis	How missing data is managed (e.g., when participants drop out/refuse to participate in certain tests).
Severity	Inclusion of all adverse reactions versus limited inclusion in relation to severity.
Size of study	Larger studies including wide range of participants provide data that are more accurate but there are significant costs involved.

Limitations of the available diagnostic methods make it difficult to diagnose food allergy or to prove an immune mechanism is involved. Most researchers agree the gold standard for diagnosis is a double blind placebo controlled food challenge (DBPCFC). For a DBPCFC, multiple test samples are presented to the patient (at different times) and neither the patient nor the physician knows which of the test samples contain the food (Metcalf, Sampson et al. 2008). This means there is the least chance for bias (from the patient or from the physician) when they monitor for symptoms (Metcalf, Sampson et al. 2008). However, this method of diagnosis can only prove that a consistent adverse reaction occurs but not the mechanism of the reaction (i.e., whether the immune system is involved). It has also been commented that results based on DBPCFC have a tendency to underestimate food allergy (Sicherer 2011). This is likely to be related to the fact that people who have experienced severe reactions are unlikely to consent to DBPCFC testing. This is reflected in the low consent rates for oral food challenge testing in a birth cohort study that assessed children at 1, 2, and 3 years of age (e.g., around 15-60% depending on age and test type – open versus double-blind placebo-controlled) (Venter, Pereira et al. 2008). In addition, DBPCFC results are only considered positive if a reaction is perceived after eating the samples containing the test food but not after eating the placebo sample. Oral food challenges can also be done ‘openly’ (the patient knowingly eats the food in its natural form) or ‘single-blind’ (the food is masked so the patient does not know whether it is present in the test substance).

A detailed discussion of diagnostic tests for food allergies can be found in Metcalf, Sampson et al. (2008). In summary, in vitro lab tests that have been clinically confirmed as useful markers for the diagnosis of food allergies include detection of food-specific IgE antibodies in the blood (IgE-mediated allergy only), and detection of specific IgG and IgA antibodies in the blood (coeliac disease only). Skin prick testing is an in vivo method commonly used to aid the diagnosis of IgE-mediated food allergies, but should be used in combination with a detailed history of symptoms as ‘false positives’ can occur. Other tests (including total serum IgE, and IgG or IgA antibodies for allergies other than coeliac disease) have no confirmed value in the diagnosis of food allergy (Metcalf, Sampson et al. 2008). The lack of diagnostic tests for non-IgE-mediated food allergies (with the exception of coeliac disease) presents a major limitation in the confirmation of immune involvement even when a consistent reaction has been shown using oral food challenges. This means the majority of non-IgE-mediated food allergies

will either not be included in prevalence data for food allergies (if data is based on oral food challenge plus diagnostic test results), resulting in an underestimation of the true prevalence; or the prevalence will be overestimated due to inclusion of non-allergic food hypersensitivity (if data is based on oral food challenge results only).

In 2011, a large scale ($N = 5000$) population-based study in Australia found 10% of 12 month old infants were affected by IgE-mediated food allergy (Prescott and Allen 2011). A large scale population-based study ($N > 12,000$) is currently underway in Europe using multinational birth cohorts in nine European countries (Iceland, UK, Netherlands, Germany, Poland, Lithuania, Spain, Italy, and Greece) (Keil, McBride et al. 2010). The study will include diagnostic testing for food allergies (food-specific IgE, skin prick testing, and DBPCFC) for children whose parents report symptoms that may be food allergy related (at any age) and selected controls with no reported symptoms. Symptomatic children and controls will undergo follow-up testing at 12-month intervals after the first diagnostic tests to determine if food allergy has resolved. It is expected that this study will give valuable information about the true prevalence of food allergies in European children. Nested case-control studies are also being undertaken in Europe, investigating the prevalence of food allergies in older children (7-10 years) and adults (Kummeling, Mills et al. 2009).

There is no data on the prevalence of diagnostically confirmed food allergies in New Zealand as no large scale systematic studies have been completed. A preliminary study investigating parent/caregiver-reported adverse reactions to food in New Zealand children (aged 0-5 years), found 40% of the children who participated experienced an adverse reaction to food (including 25% with reactions occurring within 2 hours of consumption, suggesting IgE-mediated immune involvement) (Crooks 2010). The authors note there may have been a bias towards participation (66% of 152 parents/caregivers approached agreed to participate) among parents/caregivers of children who experienced adverse food reactions, which could result in an overestimation of prevalence. However, even when calculating the percentage based on the number approached ($N = 152$), a high percentage (29% total, 18% with reaction within 2 hours) of the group experienced adverse reactions to food. Interestingly, only four of the children had their allergies investigated by a doctor. These children had a confirmed diagnosis of food allergy for peanut (4/4); cow's milk (3/4); egg (3/4); and soy (3/4). What is particularly troubling from this research is that two children had been hospitalized

because of an adverse food reaction, yet their allergies had not been investigated. The ethnicity of the children included in the study represented several of the major ethnic groups in New Zealand (e.g., NZ European, Māori, Pacific island, Asian). No statistically significant differences were found between the different groups. Based on these results, Crooks (2010) concluded that food allergy appears to impact on all the ethnic groups in New Zealand. However, further research is needed in the form of a large-scale comprehensive prevalence study that includes food allergy testing of suspected cases.

Table 2.3 summarizes the estimated prevalence rates of allergy to different food allergens (IgE-mediated food allergies) as reported by Sicherer (2011) in a recent comprehensive review of international literature related to the epidemiology of food allergy. The range given for the prevalence of gluten allergy is based on data for gluten-sensitive enteropathy (intestinal manifestation of coeliac disease) from various locations around the world (Dubé, Rostom et al. 2005, Metcalfe, Sampson et al. 2008, Makharia, Verma et al. 2011). The prevalence of other manifestations occurring independently from gluten-sensitive enteropathy has not been determined.

2.1.1.5 Summary

The understanding of what food allergies are differs between and within different sub-groups of the population (e.g., medical professionals and the general public). The World Health Organization has attempted to streamline the understanding of food allergies by promoting new nomenclature, but differences in how food allergy is defined are still evident in food allergy-related publications. While any food has the potential to cause an allergic reaction, the majority of allergic reactions are caused by a small number of foods. Symptoms of food allergy can affect single (e.g., the skin, respiratory tract, or gastrointestinal tract) or multiple organ systems (e.g., anaphylaxis). Published prevalence studies have differed in their selection criteria, diagnostic methods, and how food allergy was defined therefore the exact prevalence of food allergies is not known, but is estimated to fall between 2-10% of the general population (Sicherer 2011). Further comprehensive prevalence studies are needed (including both IgE-mediated and non-IgE-mediated food allergies) to understand the true prevalence of food allergies worldwide and in New Zealand. There is also some evidence to suggest that the number of food allergies is increasing, however, differences between published prevalence studies make a valid comparison difficult.

Table 2.3 Estimated allergy prevalence rates for common food allergens (adapted from Sicherer 2011)

Allergen	Prevalence range
Milk	0.5-3.8% of children; 0.4-0.9% of the general population
Egg	1.8-2.0% of children; 0.2-0.3% of the general population
Peanut	0.2-1.9% of children; 0.6-0.7% of adults
Tree nuts	1.1-1.6% of children; 0.5-1.0% of adults; 0.1-4.3% of the general population
Fish	0.2-0.5% of children; 0.5-0.6% of adults; 0.3-0.5% of the general population
Shellfish	0.5% of children; 5.2% of adolescents (in Singapore); 1.7-2.5% of adults; 0.6-2.0% of the general population
Soy	1.4% of children; up to 0.7% of the general population
Seeds	0.6% of children; < 1.0% of the general population
Wheat	0.4-0.5% of children; up to 0.5% of the general population
Fruit	1.2% of children; 0.1-4.3% of the general population
Vegetables	0.1-0.3% of the general population
Raw fruit/vegetables (oral allergy syndrome)	17.0% of young adults (Denmark)
Gluten (coeliac disease)	0.5-2.0% of the general population

Note: General population figures include all ages (adults and children).

2.1.2 Quality of life research

The focus of this thesis is on understanding how food allergies impact on quality of life. It is therefore important to examine and understand what quality of life is and how it can be measured. This section includes a discussion of how quality of life is defined and the methods that are commonly used in quality of life research.

2.1.2.1 What is quality of life?

The meaning of quality of life has been the subject of much debate and different attempts to define quality of life are discussed in a range of publications (e.g., Fayers and Machin 2007, Barofsky 2012, Sirgy 2012). Quality of life is a term that is commonly used, yet poorly defined. This is partly because the term ‘quality of life’ can take on different meanings in different contexts (Fayers and Machin 2007). Abstract concepts like quality and quality of life are difficult to define and researchers have employed various strategies, such as measurement approaches and content-based definitions, in their attempts to define quality of life (Barofsky 2012). Concepts such as happiness, emotional well-being, life satisfaction, subjective well-being, perceived quality of life, and psychological well-being are commonly used to represent the meaning of quality of life (Sirgy 2012). While some researchers focus on objective indicators such as health, income, crime, and education, others choose to take a subjective approach, using indicators such as happiness, life satisfaction, and psychological well-being (Sirgy 2012). In terms of individual quality of life, subjective well-being is considered a good indicator as it encompasses how well one’s emotional state and different aspects of life meet a person’s standards or expectations for life (Efklides and Moraitou 2013).

2.1.2.2 Quality of life and consumer research

Transformative consumer research is a branch of consumer research that is concerned with the well-being of consumers. Researchers in this field concentrate their efforts on research that will benefit consumers and improve their overall well-being (Ozanne, Pettigrew et al. 2011). Consumer vulnerability is a term used in consumer research to describe a loss of control experienced by consumers and a dependence on external factors to meet their consumption needs (Baker, Gentry et al. 2005). The experience of consumer vulnerability will affect subjective well-being because if a consumer’s consumption goals cannot be met, then that aspect of their life will not meet their expectations. Consumer vulnerability is therefore an important consideration for consumer-focused quality of life research.

2.1.2.3 Quality of life in the health sector

Traditionally, the main focus for treatment outcomes was based around physical measures (i.e., the removal of symptoms related to the disease being treated) (Fairclough 2010). It has become more recognized now that a patient's perception of his/her well-being following treatment is an important health outcome (Fairclough 2010). This has given rise to the concept of quality of life, which refers to a person's well-being and satisfaction. The World Health Organisation (WHO) defines health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (World Health Organisation 1948, p. 1). Health-related quality of life brings these concepts together, looking at the personal burden of living with a particular health condition. Health-related quality of life can be defined as "the functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient" (Baiardini, Braido et al. 2006, p. 420). It takes into account the effects a medical condition or its treatment have on the physical, emotional, and social well-being of an individual, and in many cases also takes into consideration the economic impact (e.g., cost of living and impact on income) (Fairclough 2010).

Health-related quality of life differs from generic quality of life in that it evaluates health-related aspects of quality of life (i.e., how an individual's health impacts on their quality of life) while excluding the impact of other aspects of life. A further distinction exists within health-related quality of life where measures may be generic or disease-specific. Generic health-related quality of life measures assess general physical, mental, and social functioning and are useful for the comparison of patients with different diseases and/or comparison with healthy controls (Fairclough 2010, Flokstra-de Blok, Dubois et al. 2010, Flokstra-de Blok and Dubois 2012). However, because of their lack of specificity, generic measures may be less sensitive to disease specific problems and do not distinguish problems from comorbid diseases (Flokstra-de Blok, Dubois et al. 2010). In contrast, disease-specific health-related quality of life measures are targeted to a specific disease and therefore are more sensitive to the problems of that disease and are more responsive to changes in health-related quality of life (Fairclough 2010, Flokstra-de Blok, Dubois et al. 2010, Flokstra-de Blok and Dubois 2012).

Health-related quality of life research is important to ensure treatments and/or interventions being used are having the desired effect of restoring a patient's health to as close as possible to the WHO definition of health. It 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 the treatment has a high impact on a patient's quality of life (e.g., by way of side-effects of a treatment drug, or social implications), it can have a number of implications for their long-term health. For example, it has been shown that the perceived burden of a treatment will affect treatment compliance. Patients are less likely to continue with a treatment if they feel it has a high impact on their quality of life (Martin, Haskard-Zolnierek et al. 2010). This 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). In addition, if a condition or its treatment is a source of continued stress, this accumulation of stress can result in a vulnerability to further physical health problems. Continual activation of the body's stress response has been linked to lowered immunity (more likely to succumb to bacterial and viral infections), and the development of insulin resistance disorders, cardiovascular disease, and mental health problems (e.g., anxiety and depression) (Sapolsky 2004).

2.1.2.4 Research methods in health-related quality of life research

Research methods can be divided into two main categories: qualitative methods and quantitative methods. Qualitative methods are useful for increasing the understanding of what, how, and why in relation to experiences, behaviours, and opinions. Qualitative research methods commonly used to investigate health-related quality of life include one-on-one interviews and focus groups. In contrast, quantitative methods focus on quantifying a phenomenon of interest, answering questions about how much, and how often. For example, how many people experienced a health issue, how often people experienced that health issue, and the level of stress or pain experienced. The main form of quantitative research on health-related quality of life involves the use of surveys. A brief description of what these methods entail, the type of data that is obtained, and the merits and limitations of each method are presented in Table 2.4 (summarized from Saks and Allsop 2007).

Table 2.4 Overview of common qualitative and quantitative research methods used for health-related quality of life research

Description of method & information gained	Merits of method	Limitations and considerations of method
<i>Qualitative methods:</i>		
<u>One-on-one in-depth interviews</u>		
<p>Participants are usually selected for their specific knowledge in relation to the research question.</p>	<p>Can provide in-depth information about the perspectives of the participants, stated in their own words, and allows for answers to how and why questions in relation to certain behaviours or feelings.</p>	<p>Statistical generalizations are not possible.</p>
<p>Not totally without structure as it must be informed by a research question or questions.</p>	<p>The beliefs, perceptions, and experiences of individual participants can be seen as an indication of wider socio-cultural features or social processes.</p>	<p>Requires more investment of time and emotional energy from both the participants and the researcher than other methods.</p>
<p>Questions should be open-ended and as non-directive as possible. Typically opens with a question that encourages the informant to start talking without directing the content, followed by questions based on what the informant says and prompts to keep the conversation flowing.</p>		<p>The credibility of the research will depend upon how the findings are presented.</p>
<p>Used to give in-depth information about individual participants' experiences and feelings.</p>		<p>The data will accurately represent what the participants are willing to reveal but not necessarily what they truly do or think.</p>
		<p>The data is based on retrospective interpretations and descriptions of events from the participants' past so cannot be used to represent their experience at the actual time it occurred.</p>

Table 2.4 Overview of common qualitative and quantitative research methods used for health-related quality of life research, continued.

Description of method & information gained	Merits of method	Limitations and considerations of method
<p><u>Focus groups</u></p>		
<p>A focus group is a group interview. Typically, it involves a group of 6-12 people, and one or more facilitators.</p>	<p>Participants can frame their concerns in their own terms and bring up issues the researchers may not have thought of.</p>	<p>Need to consider hierarchical relations within the group (some may not get the opportunity to participate fully).</p>
<p>The facilitator introduces the discussion topic, then guides, and records the discussion.</p>	<p>Analysing discussion rather than just individual opinions allows complexity of views to be studied.</p>	<p>To provide convincing data for policy makers the sample must be representative (to be considered credible).</p>
<p>Used to learn what people know (identify participants' perspectives), how they know it (understand their frames of meaning), and how the knowledge is communicated in social interaction.</p>	<p>Useful for generating data for survey design.</p> <p>Small number of groups can generate large data sets.</p>	<p>May not provide as much in-depth information about each participant's individual views/perspectives as one-on-one interview technique.</p>
<p>Focus groups that are based on population samples (people from different backgrounds) can be used to demonstrate the range of views about an issue.</p>	<p>Group interaction can allow more 'naturalistic' talk about the topic (but need to control discussion if aim is to access range of views).</p> <p>Supportive environment to discuss sensitive issues (others in the group can legitimize negative views).</p> <p>One participant's story can trigger other participants' recollection.</p>	<p>Identifying participants and organizing groups can be resource intensive.</p>

Table 2.4 Overview of common qualitative and quantitative research methods used for health-related quality of life research, continued.

Description of method & information gained	Merits of method	Limitations and considerations of method
<i>Quantitative methods:</i>		
<u>Quantitative surveys</u>		
<p>Can be ad hoc (one-off survey), cross-sectional (regular surveys monitoring trends over time), longitudinal (survey repeated on same cohort at different times), or real-time (surveys monitoring current behaviours and experiences).</p> <p>The most common ways to collect survey data are postal, telephone, and face-to-face surveys.</p>	<p>Survey methods are useful for examining comparisons and variations between groups, and for providing a broad overview of a social phenomenon.</p> <p>Real-time surveys remove or reduce the bias of autobiographical memory and allow within-person comparisons (e.g., comparison of day-to-day changes for individuals).</p>	<p>Not able to capture meanings and perceptions in context. Surveys involve measurement but not all social phenomena are measurable.</p> <p>Postal surveys are less costly but are prone to a larger response bias, usually do not use open-ended questions or control question sequence, and may not get answers to all the questions completed.</p> <p>Telephone surveys have higher response rates than postal but are more costly, more difficult to implement, and not useful for sensitive topics.</p> <p>Face-to-face surveys provide the best response rates but are costly, and slow to implement, and the quality of the answers may be affected.</p> <p>Real-time surveys cannot be used to collect historical data.</p>

In the context of quality of life research where the researcher is interested in understanding the range of experiences and opinions of different members of a target group, focus groups have several advantages over in-depth interview methods. First, focus groups provide a supportive environment. If the sample is appropriately selected, a supportive environment is created by including participants with shared experiences and/or areas of concern (Liamputtong 2011). For example, in the context of understanding the experiences and issues of adults with food allergies, participants will feel more comfortable discussing their experiences with other adults with food allergies because they are more likely to understand. In addition, the participants outnumber the researcher in a focus group setting, reducing any imbalance in power relationships between the participants and the researcher (Liamputtong 2011). Second, by including people from different backgrounds, focus groups can demonstrate both similarities and differences in experiences within the target group (Liamputtong 2011). During a focus group, participants discuss experiences and issues among the group, comparing with each other and challenging others' opinions. This helps to draw out different points of view and the reasoning behind opinions and behaviours related to their experiences. Third, one participant's story can trigger other participants' memory of their own experiences that might otherwise not have been shared. Finally, the interaction among participants in focus groups creates more emphasis on the participants' views as opposed to the views of the researchers (Liamputtong 2011). This helps ensure the direction of the discussion is not controlled by the prior knowledge/opinions of the researcher, allowing access to potentially novel information.

Survey methods commonly used for health-related quality of life research involve the use of either generic or disease-specific instruments. Generic instruments are advantageous to use when comparing different groups (e.g., those with a particular disease vs the general population) or to compare the status of subjects at different stages of their disease or treatment (Fairclough 2010). Disease-specific instruments give more detailed information about the particular impact of a specific disease and/or its treatment and are therefore more sensitive for picking up changes as a result of a treatment or intervention (Fairclough 2010). These instruments are commonly used with cross-sectional or longitudinal survey methods.

As health-related quality of life is based on an individual's perception, it can only be measured by using self-reports which can be influenced by other factors unrelated to

the illness being investigated. Emotional, social, and cognitive factors, expectations and coping style all affect personal perception (Cummings, Knibb et al. 2010). For example, people from different social worlds (reflecting variation in each individual's culture, gender, and age) will experience different meanings and understandings of an event or illness based on the 'norms' of their particular social world (Lyons and Chamberlain 2006).

A limitation of commonly used health-related quality of life information gathering methods is that they involve participants having to recall and report on experiences from their past. Ideally, that would involve participants thinking back and accurately describing an event from their past or remembering how often something occurred during a particular period of time (e.g., the past month). Unfortunately, autobiographical memory is not entirely accurate. The reality is that even relatively important events in people's lives can be forgotten as time passes and frequent behaviours are unlikely to be remembered on an individual basis (Weaver and Schwarz 2008). During interviews, recall can be improved by using interviewing techniques that are based on an in-depth knowledge of the workings of autobiographical memory; however, such techniques cannot be employed when retrospective data is collected using questionnaires (Schwarz 2007). Real-time (or near to real-time) data capture methods allow participants to report on their current behaviours and experiences, thus removing the bias introduced by the limitations of autobiographic memory (Schwarz 2007). The rationale for using real-time data capture methods in place of retrospective reports is discussed in detail by Schwarz (2007). The main types of data collection for which real-time data capture methods are preferable are summarized below:

Frequency (for frequent and irregular behaviours/experiences): Our memory collates information about highly similar frequent events in the form of a global knowledge-like representation, which makes individual incidences indistinguishable and irretrievable. Respondents therefore rely on an estimation strategy when asked to recall the frequency of such events, which may not provide an accurate representation of the true frequency.

Intensity (e.g., how painful or how stressful?): Peak and end effects complicate retrospective reports related to intensity during memorable events (e.g., pain during a medical procedure). This means when patients

are asked to report on the intensity of a sensation (e.g., pain), their answer will be based on a combination of the highest intensity they experienced during the time period in question (the peak) and the most recent intensity they experienced (the end). When asked to report on intensity of chronic or recurrent experiences, the reported intensity will be a function of the respondent's current state. Asking patients to report on intensity at frequent intervals throughout the time of their experience will provide a more accurate picture of their overall experience.

Changes over time: The only way to provide reliable data on changes over time is to use concurrent measures at the different points in time that are of interest. Retrospective reports on changes over time will be biased due to theory-driven inferences used by respondents, particularly if a plausible theory is suggested by the context. For example, if a patient is asked to report on their current condition in relation to their condition prior to a treatment, the patient is likely to infer that their condition must have improved because that is what the treatment was for.

Causation (e.g., why did they feel stressed?) and covariation (e.g., what were the circumstances?): These types of questions can only be answered accurately if respondents are able to access accurate information about the frequency, contexts, and intensity of experiences. However, as discussed above, respondents generally cannot accurately report on these individual components so it would be unrealistic to expect them to be capable of accurately recalling information about their interaction.

Daily diary methods involve collection of data in 'near to real time' and encompass many similar advantages to real-time methods. While daily diary methods still involve a degree of retrospection, and therefore possible recall bias, they are less demanding than true real-time methods (Schwarz 2007). In addition, certain types of data (e.g., reporting the occurrence of specific events) are less bias-prone and therefore better suited to daily diary methods compared to other types of data (e.g., reporting how often a frequent and ordinary event occurred). Unlike cross-sectional surveys, daily diary methods can also assess the within- and between-person associations between predictors and outcomes. Retrospective reports can be useful for the collection of historical

information (e.g., ‘when were you first diagnosed?’, or ‘have you ever experienced an anaphylactic reaction?’), and frequency of rare or regular frequent behaviours or experiences (Schwarz 2007). In fact, it is the only available method for the collection of historical information.

2.1.2.5 Summary

Quality of life can mean different things depending on the context. Subjective well-being is a good indicator of overall individual quality of life. Consumer vulnerability, a term commonly used in consumer research, is an indicator of subjective well-being in the context of a consumer’s consumption goals. The term used to represent quality of life in health research is ‘health-related quality of life.’ Health-related quality of life reflects the effects of a medical condition and its treatment on physical, emotional, social, and economic well-being, while excluding the impact of other aspects of life. It is important to understand quality of life in the context of a medical condition to ensure treatments/interventions meet the WHO goal for health (i.e., complete physical, mental, and social well-being). Both qualitative and quantitative research methods provide valuable information about health-related quality of life. In terms of the impact of food allergies on quality of life, qualitative methods can provide answers to what (e.g., what issues individuals with food allergies face), how (e.g., how individuals with food allergies feel about their food allergy-related experiences), and why (e.g., why certain behaviours/responses to experiences occur). Focus groups are useful for accessing a range of experiences and opinions from different members of a target group (e.g., individuals with food allergies). Quantitative methods can provide answers about how much (e.g., how many individuals experienced a particular issue, the level of impact of that issue on quality of life) and how often (e.g., how often an individual experiences and issue). Daily diary methods are easier to implement than true real-time methods and are well suited for collecting information about the day-to-day occurrence of specific events or issues and determining associations between predictors (e.g., food allergy-related issues) and outcomes (e.g., quality of life indicators).

2.1.3 Mixed methods research

An increased recognition of mixed methods approaches is evident in quality of life research, driven by the desire of health researchers to improve the quality and scientific power of data (Klassen, Creswell et al. 2012). Mixed methods research, often referred to as the third research paradigm, recognises that both qualitative and quantitative methods are important and useful, drawing on the strengths of each approach to produce data (Doyle, Brady et al. 2009, Johnson and Onwuegbuzie 2004, Johnson, Onwuegbuzie et al. 2007). In mixed methods research both qualitative and quantitative data is collected, analysed, and interpreted to investigate a single underlying phenomenon (Leech and Onwuegbuzie 2009). The following sections will include a discussion of the theoretical underpinnings and methodological elements of mixed methods research.

2.1.3.1 Theoretical underpinnings of mixed methods research

How we should view the world and understand knowledge is an ongoing debate that dates back to ancient Western philosophy (Johnson, Onwuegbuzie et al. 2007). Qualitative (constructivist) and quantitative (positivist) paradigms have long influenced researchers' questions and the methods they use to answer them (Doyle, Brady et al. 2009). While mixed methods research attempts to respect the underlying philosophies of both qualitative and quantitative approaches to access knowledge, the primary philosophy of mixed methods research is pragmatism (Johnson, Onwuegbuzie et al. 2007). According to Cornish and Gillespie (2009, p. 800), pragmatism views knowledge as "a tool for action" that "should be evaluated according to whether it serves our desired interests." Pragmatism focuses on the purpose and consequences of knowledge rather than the underlying reality of knowledge (Cornish and Gillespie 2009). For this reason, pragmatism judges knowledge according to whether it works to solve everyday problems, allowing researchers to combine methods that offer the best chance of answering their research questions (Cornish and Gillespie 2009, Doyle, Brady et al. 2009).

2.1.3.2 Mixed methods research design

As discussed in section 2.1.3.1, the pragmatic view driving mixed methods research means that study design is predominantly determined by how well the methods can answer the research questions. Basic considerations involved in designing mixed

methods research include whether the design should be fixed or emergent, concurrent or sequential, if the priority between qualitative and quantitative methods should be equal or not, and if the mixing (integration) between methods should occur during data collection, data analysis, or data interpretation (Creswell, Klassen et al. 2011, Doyle, Brady et al. 2009, Klassen, Creswell et al. 2012). A fixed design means the methods are determined at the beginning of the research, based on a decision by the researchers to mix qualitative and quantitative approaches to answer their research question (Klassen, Creswell et al. 2012). In contrast, an emergent design involves choosing the methods during the process of the research. Concurrent designs merge data that are collected concurrently and compare the two sets of data while sequential designs allow one data set to build on the results of the other (Klassen, Creswell et al. 2012). As discussed by Creswell, Klassen et al. (2011), integration of qualitative and quantitative data can be approached in different ways (merging data, connecting data, or embedding data). Integrating data by merging involves combining the qualitative data (texts or images) with numerical quantitative data (e.g., reporting the results together in the discussion of a study). Connecting data involves using the results from one dataset to inform the data collection from the next phase of research. When integration is achieved by embedding data a supplementary dataset is embedded within a larger primary design.

Doyle, Brady et al. (2009) describe the typology of mixed methods designed by Creswell and Plano Clark (2007) in terms of four main research designs: triangulation, embedded design, explanatory, and exploratory. Each of these designs are associated with a particular process. Triangulation is the most well-known design but is also viewed as the most challenging. The triangulation design involves concurrent timing of qualitative and quantitative methods, with equal weighting given to both methods, and integration occurring at the interpretation phase (Doyle, Brady et al. 2009). The embedded design involves the use of one dominant method that provides the main data set, and a supplementary method that provides secondary supportive data. The explanatory design begins with a quantitative phase, followed by a qualitative phase that enhances or explains the quantitative results. Although the explanatory design can be time-consuming because of its sequential nature, it is considered the easiest of the four designs to implement. The exploratory design is also sequential but begins with a qualitative phase that informs the development of the quantitative phase. Creswell and Plano Clark (2011) describe two additional designs: the transformative design

(transformative theoretical framework shapes the mixed methods design) and the multiphase design (a combination of both sequential and concurrent phases).

Leech and Onwuegbuzie (2009) describe the typology of mixed methods research in terms of three dimensions: level of mixing, timing (concurrent or sequential), and emphasis of approaches (dominant or equal status). Partially mixed studies mix qualitative and quantitative data at the interpretation stage while fully mixed studies are also mixed in earlier phases of the research (e.g., research objectives, types of data, analysis, and/or inference). Classification using this system results in eight mixed methods designs: 1. Partially mixed concurrent equal status; 2. Partially mixed concurrent dominant status; 3. Partially mixed sequential equal status; 4. Partially mixed sequential dominant status; 5. Fully mixed concurrent equal status; 6. Fully mixed concurrent dominant status; 7. Fully mixed sequential equal status; 8. Fully mixed sequential dominant status (Leech and Onwuegbuzie 2009). An advantage of this classification system is that it is simple and easy to understand (Doyle, Brady et al. 2009).

2.1.3.3 Mixed methods in the current research

The underlying philosophy for the research described in this thesis is pragmatism, although the qualitative portion (Study 1) takes a largely interpretivist perspective (see Chapter 3, section 3.3.2). The mixed methods approach used resembles the exploratory design of Creswell and Plano Clark (2011) or the fully mixed sequential equal status design of Leech and Onwuegbuzie (2009). The aims of the research included both qualitative and quantitative aspects, which were addressed by starting with a qualitative method (phase 1) which informed the development of the quantitative method (phase 2). Further integration of the qualitative and quantitative methods occurred in the data interpretation phase (see Chapter 5), with equal status given to the datasets.

2.2 Food allergies and quality of life

As with any chronic health condition, it is important to know in what way/s having a food allergy and the associated treatment (i.e., eliminating the allergenic food from the diet) affects the quality of life of people with food allergies. That is the purpose of health-related quality of life research. Currently, there is no medically verified method of treatment for food allergies other than to completely avoid the food/s responsible for

the reaction. The resulting dietary and lifestyle changes are likely to have an impact on quality of life and this impact will differ from that of other chronic health conditions. Information about how and why their quality of life is impacted will allow the development of appropriate interventions to improve the lives of individuals with food allergies, resulting in better management of the condition and reduced long-term health effects.

Research on the health-related quality of life of children and adolescents with food allergies, the parents of children and adolescents with food allergies, and adults with food allergies has shown that their health-related quality of life is significantly impaired (Sicherer, Noone et al. 2001, Marklund, Ahlstedt et al. 2006, Östblom, Egmar et al. 2008, Flokstra-De Blok, Dubois et al. 2010). Recent international research comparing people with food allergies to people with other chronic health conditions found the health-related quality of life of individuals with food allergies to be poorer than the health-related quality of life of individuals with diabetes (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 yet, compared to diabetes, food allergy is underrepresented in terms of research publications. The following sections present a discussion of publications on food allergy-related quality of life in children/adolescents with food allergies and their parents (Section 2.2.1) and adults with food allergies (Section 2.2.2).

2.2.1 Children/adolescents with food allergies and their parents

The results of both generic and food allergy-specific measures have shown an impact of food allergies on the quality of life of children and adolescents with food allergies, and/or their parents (Primeau, Kagan et al. 2000, Sicherer, Noone et al. 2001, Avery, King et al. 2003, Cohen, Noone et al. 2004, Bollinger, Dahlquist et al. 2006, King, Knibb et al. 2009, LeBovidge, Strauch et al. 2009, Leung, Yung et al. 2009, Flokstra-De Blok, Dubois et al. 2010, Lieberman, Weiss et al. 2010, Resnick, Pieretti et al. 2010). Primeau, Kagan et al. (2000) investigated the parent-reported quality of life of 153 peanut allergic children (mean age = 6.4 years, $SD = 4.0$) compared with 69 children with rheumatological disease. Parents of peanut allergic children reported more disruption to daily activities and a greater negative impact on familial/social interaction compared with

parents of children with rheumatological disease. Low response rates for this study (peanut allergic children 58%, children with rheumatological disease 39%) and the presence of comorbidities may have introduced sample bias in these results. Sicherer, Noone et al. (2001) investigated the parent-reported quality of life of 253 food-allergic children (mean age = 10.8 years, range = 5 – 18 years) using a generic measure of child health. Compared with previously reported means for a US population sample of children, food-allergic children were reported to have lower mean scores in the domains of mental health, general health, and family activities and their parents experienced more distress and worry. A limitation of both of these studies is that accessing the opinions of the parents/caregivers rather than the children may not accurately reflect the actual quality of life of these children. This concern is supported by the findings of King, Knibb et al. (2009) and LeBovidge, Strauch et al. (2009) who found that parents of food-allergic children (particularly mothers) tended to report a higher impact on the quality of life of their children compared with the reports of the children themselves.

Cohen, Noone et al. (2004) developed a disease-specific instrument to measure the parental burden of having a child with a food allergy. Results showed an impact of food allergy on family and social activities, time, health and nutritional concerns, and emotional issues (e.g., anxiety about reactions, frustration when dealing with others, sadness, and worry about the child). A limitation of this measure is that the parents of food-allergic children who were involved in the development and validation process were predominantly white and of high socio-economic status. The disease-specific instrument developed by Cohen, Noone et al. (2004) was translated and adapted by Leung, Yung et al. (2009) for use with Chinese families of food-allergic children. The translated questionnaire was completed by 197 parents of Chinese children with adverse food reactions (mean age = 4.2 years, *SD* = 6.9). Leung, Yung et al. (2009) reported a higher impact on quality of life for parents of children with adverse reactions to more than three foods.

Lieberman, Weiss et al. (2010) investigated the experience of food allergy-related bullying among food-allergic individuals (mostly children aged 11 years or younger, 80.9%). Overall, 24.1% of the participants reported bullying, teasing, or harassment because of their food allergy, which is likely to impact on quality of life directly (i.e., emotional impact) and indirectly (e.g., by encouraging disclosure avoidance and risk-taking behaviour).

LeBovidge, Strauch et al. (2009) investigated parent-reported (children aged 2 – 17 years, $n = 141$) and self-reported (children aged 8 – 17 years, $n = 69$) psychological distress among food-allergic children and adolescents. The child-report scores for anxiety found that food-allergic children reported higher on anxious coping and separation/panic sub-scales compared to normative scores. King, Knibb et al. (2009) investigated the impact of peanut allergy on the quality of life of families with a peanut-allergic child ($n = 46$). Children with peanut allergy had poorer physical health-related quality of life, quality of life at school, and general quality of life, and experienced greater separation anxiety compared with their siblings. Mothers of peanut-allergic children reported worse psychological and physical quality of life, and experienced greater anxiety and stress compared with the fathers of peanut-allergic children. This may reflect a higher involvement of mothers in the daily management of their child's peanut allergy.

Avery, King et al. (2003) compared the quality of life of children with peanut allergy ($n = 20$, mean age 9.0 years) and children with insulin-dependent diabetes ($n = 20$, mean age = 10.4 years) aged between 7 and 12 years old using two disease-specific questionnaires. Children with peanut allergy were found to have a lower quality of life compared to children with diabetes, particularly in the areas of anxiety and fear. However, the small number of participants included in this pilot study limits the generalizability of these results. Flokstra-De Blok, Dubois et al. (2010) compared the health-related quality of life of children (8 – 12 years, $n = 79$) and adolescents (13 – 17 years, $n = 74$) with physician-diagnosed food allergies to previously published quality of life figures for the general population and individuals with other chronic diseases. The quality of life of children with food allergies was not found to be impaired compared to the general population, and could not be compared with other chronic diseases because there was no data available. Adolescents with food allergies reported lower quality of life compared to the general population (bodily pain and general health scales), and lower quality of life compared to adolescents with diabetes (physical functioning, bodily pain, mental health, and self-esteem scales). Resnick, Pieretti et al. (2010) developed a disease-specific questionnaire for food-allergic adolescents. The final questionnaire was completed by 203 food-allergic adolescents (13 – 19 years). The results showed that, on average, food-allergic adolescents were moderately troubled by limitations on social activities, not being able to eat what others were eating, and limited choice of restaurants.

Qualitative studies exploring the experiences and perspectives of children and adolescents with food allergies support these quantitative findings, reporting an impact on psychological development (DunnGalvin, Gaffney et al. 2009), psychological functioning (e.g., stress, anxiety, sadness, frustration, feeling overburdened, feeling deprived) (Marklund, Wilde-Larsson et al. 2007, MacKenzie, Roberts et al. 2010, Fenton, Elliott et al. 2011), and social activities (Marklund, Wilde-Larsson et al. 2007, MacKenzie, Roberts et al. 2010, Pitchforth, Weaver et al. 2011). A discussion of what is known about food allergy issues, much of which is based on research with food-allergic children/adolescents and their parents, is included in Section 2.2.3.

2.2.2 Adults with food allergies

Quality of life-related research involving adults with food allergies is limited internationally (12 publications), and non-existent in New Zealand. Three quantitative publications compared individuals with food allergies with the general population, and/or individuals with other diseases such as asthma, diabetes, irritable bowel syndrome, and rheumatological disease (Primeau, Kagan et al. 2000, Roos, Karner et al. 2006, Flokstra-De Blok, Dubois et al. 2010). One quantitative publication compared the food allergy-specific health-related quality of life of American and Dutch adults using a validated food allergy-specific health-related quality of life measure (Goossens, Flokstra-de Blok et al. 2011). The other two quantitative publications investigated specific quality of life-related topics, such as the bullying, teasing, and harassment of individuals with food allergies (Lieberman, Weiss et al. 2010) or the effect of food allergies on cost of living (Voordouw, Fox et al. 2010).

Flokstra-De Blok, Dubois et al. (2010) compared the health-related quality of life of food-allergic adults ($n = 72$, mean age = 37.2 years) with the general population and other chronic diseases using a generic health-related quality of life questionnaire. The health-related quality of life of adults with food allergies was found to be poorer than that of the general population (social functioning, vitality, and general health scales) and adults with diabetes (social functioning, role functioning-physical, vitality, bodily pain, and general health scales), but better than that of adults with asthma, rheumatoid arthritis, or irritable bowel syndrome. Primeau, Kagan et al. (2000) compared the burden of peanut allergy to the burden of rheumatological disease. Peanut-allergic adults ($n = 37$, mean

age = 30.9) and adults with rheumatological disease ($n = 42$, mean age = 35.4) completed self-report questionnaires about the level of disruption their allergy/illness caused in their lives. It was found that adults with peanut allergy experienced less disruption to daily activities, familial/social disruption, personal strain, and financial burden than adults with rheumatological disease. Roos, Karner et al. (2006) compared the psychological well-being of adults with coeliac disease ($n = 51$, aged 45 – 62 years) to the general population ($n = 182$, aged 45 - 64) using a validated psychological well-being questionnaire. Overall, middle-aged adults with coeliac disease in proven remission had the same psychological well-being as the similarly-aged population sample. However, the psychological well-being of women with coeliac disease was found to be significantly lower than that of men with coeliac disease, an effect not found in the general population sample.

Lieberman, Weiss et al. (2010) found that feelings of sadness, depression, embarrassment, and humiliation were common as a result of food allergy-related bullying, teasing, or harassment (67% experienced sadness/depression, 64% experienced embarrassment/humiliation). However, the study by Lieberman, Weiss et al. (2010) only included 23 adults with food allergies (6.6% of participants), with the remaining participants consisting of children with food allergies or their parents ($n = 328$), therefore the significance of these findings for adults with food allergies is not clear. A pilot study by Voordouw, Fox et al. (2010) compared the household costs in households with a food allergy ($n = 126$) to households without a food allergy ($n = 64$). Direct health care costs, indirect costs (loss of time and lost income), and intangible costs (self-perceived health and well-being) were found to be higher in households with food allergy compared to those without food allergy.

Two publications presented the results of mixed-methods quality of life-related research. One described the development of a food allergy-specific health-related quality of life measure for adults (Flokstra-de Blok, van der Meulen et al. 2009) and the other described the impact of coeliac disease on the lives of coeliac patients and their relatives (Sverker, Ostlund et al. 2009). Flokstra-de Blok, van der Meulen et al. (2009) found that adults with anaphylaxis and adults with more than three food allergies had poorer health-related quality of life compared with other adults with food allergies. While the study design used by Flokstra-de Blok, van der Meulen et al. (2009) was mixed methods, their qualitative results were used purely for questionnaire development and were not discussed

in this publication. Sverker, Ostlund et al. (2009) used a QUAL-quan mixed methods design to investigate the everyday dilemmas experienced by men ($n = 11$) and women ($n = 32$) who had coeliac disease and their close relatives ($n = 23$). The study by Sverker, Ostlund et al. (2009) found that adults with coeliac disease experienced long-lasting symptoms following accidental exposure to gluten and participants reported experiencing daily concerns about issues such as cost and loss of time, and being burdened with constant preparedness, social exclusion, and emotional pressure. Based on these results, it is evident that the daily management of coeliac disease presents similar issues to IgE-mediated food allergies.

Four publications described qualitative studies that investigated the experiences of adults with food allergies. Two of these involved participants with specific food allergies only; one focused on the experiences of adults with coeliac disease (Sverker, Hensing et al. 2005) and the other focused on challenges faced by adults with peanut and/or tree nut allergy when eating out (Leftwich, Barnett et al. 2011). From their interviews using 'The Critical Incident Technique', Sverker, Hensing et al. (2005) found that adults with coeliac disease ($n = 43$, aged 20 – 40 years) expressed feelings of isolation and shame, a fear of food being contaminated with gluten, and worry about being a bother to others. In a semi-structured interview study, Leftwich, Barnett et al. (2011) found that adults with peanut and/or tree nut allergies ($n = 32$, aged 16 - 70) expressed concern about social embarrassment, lifestyle restrictions, and loss of spontaneity and experienced anxiety about being considered 'fussy'. It is clear from these results that similarities exist in the experiences of these two sub-groups of adults with food allergies; however, there is a need for research that includes adults with a range of food allergies to explore similarities and differences in their experiences in more detail. The third qualitative publication used a sociological approach to compare the experiences of adults with food allergies ($n = 10$) and adults with food intolerance ($n = 18$) using semi-structured interviews (Nettleton, Woods et al. 2010). Based on their findings, Nettleton, Woods et al. (2010) suggested that food allergies are more socially accepted than food intolerances. The fourth qualitative publication reported the results of a focus group study that compared the food choice behaviour and related experiences of adults with medically diagnosed food allergies ($n = 12$), adults with self-diagnosed food allergies ($n = 15$), and adults with no food allergies ($n = 17$) (Sommer, MacKenzie et al. 2012). Sommer, MacKenzie et al. (2012) found that adults with food allergies were deprived of pleasure and satisfaction

from food, had difficulties finding safe food, and needed to be more organized with food compared to adults with no food allergies.

In summary, food allergen management is associated with issues that impact on health-related quality of life. As a result, the health-related quality of life of adults with food allergies is poorer when compared with the general population and adults with diabetes. However, further research is needed to fully understand how and why food allergies impact quality of life and the level of impact of food allergies on daily life. Section 2.2.3 presents a more detailed discussion of what is known about the issues related to food allergy management. Limitations of the available quality of life literature in relation to food allergies are discussed in section 2.2.4.

2.2.3 Food allergy issues

A number of important issues that have an ongoing effect on the lives of individuals with food allergies have been identified to date. These include issues related to finding safe foods, participation in social activities, medical care, the costs of having a food allergy, and psychological/emotional issues. A summary and discussion of the issues that individuals with food allergies face during the course of their lives is presented in Sections 2.2.3.1 to 2.2.3.5.

2.2.3.1 Issues related to finding safe foods

Completely eliminating one or more food from one's diet is not a simple task because processed foods are commonly used and contain 'hidden' ingredients. Initially after diagnosis with a food allergy, the individual will have to go through the process of identifying which products are 'safe foods' and which products must be avoided. Depending on the food in question, they may also have to learn to cook with a variety of alternative ingredients that can be used as a substitute for staple food ingredients (e.g., wheat or milk products). After a period of adjustment, the individual with food allergies will most likely have mastered a system for the purchase and preparation of daily foods for consumption at home. This system can still suffer from setbacks, however. For example, a manufacturer may choose to change the formulation of a product, resulting in a trusted 'safe' food no longer being free from the allergen/s in question. Research using disease-specific health-related quality of life questionnaires has found this to be a major

issue for adults with food allergies (Flokstra-de Blok, van der Meulen et al. 2009, Goossens, Flokstra-de Blok et al. 2011). This issue contributes to the need for constant vigilance to ensure the foods eaten are safe. The constant need for vigilance (e.g., having to check food labels and ask about ingredients of foods at restaurants or other social occasions) is considered to be a significant source of stress for people with food allergies and their caregivers (Marklund, Wilde-Larsson et al. 2007, Flokstra-de Blok, van der Meulen et al. 2009, Cummings, Knibb et al. 2010, MacKenzie, Roberts et al. 2010, Goossens, Flokstra-de Blok et al. 2011, Leftwich, Barnett et al. 2011).

2.2.3.2 Issues related to participation in social activities

Participation in food-related social activities is likely to continue to present a number of difficulties. Research with individuals with severe food allergies (anaphylaxis) has shown that the majority of adverse reactions to foods occur outside of the home (Uguz, Lack et al. 2005). When eating away from home, individuals with food allergies become dependent on the cooperation, understanding, and knowledge of others to ensure the safety of foods eaten. Unfortunately, the ability of others to do this can be significantly lacking. Restaurant staff, food service providers, and the general public do not necessarily have a good understanding of food allergies and what is required to ensure foods prepared are free from a particular food allergen (Ahuja and Sicherer 2007, Gupta, Kim et al. 2009, Ajala, Cruz et al. 2010).

Attitudes in relation to food allergy can also present a problem, where people may not accept that individuals with food allergies have a genuine medical reason for avoiding the food. Qualitative studies with individuals with food allergies and caregivers of children with food allergies have revealed that this is an area of concern (Marklund, Wilde-Larsson et al. 2007, McBride, McBride-Henry et al. 2010, Springston, Smith et al. 2010, Fenton, Elliott et al. 2011, Leftwich, Barnett et al. 2011). This type of attitude can result in people not taking proper precautions when preparing foods for those with food allergies and can influence individuals with food allergies to take risks to avoid being judged (Marklund, Wilde-Larsson et al. 2007, DunnGalvin and Hourihane 2009, Nettleton, Woods et al. 2010, Leftwich, Barnett et al. 2011). Both of these factors increase the risk of an adverse food reaction. Another coping mechanism used to deal with the ignorance of others towards food allergy is to simply avoid certain social situations (DunnGalvin and Hourihane 2009, McBride, McBride-Henry et al. 2010). It is

therefore likely that the ignorance of others is a major factor, not only as a regular source of stress for individuals with food allergies, but also as the main reason for most allergic reactions occurring outside of the home.

2.2.3.3 Issues related to medical care

Insufficient and inconsistent medical information creates a major barrier to coping with food allergies. This was revealed by two qualitative studies with parents of children with food allergies. The first study involved semi-structured interviews with parents ($n = 20$) of children diagnosed with anaphylaxis (Mandell, Curtis et al. 2005). Nearly all the parents felt the information provided to them at the time of diagnosis of their child was insufficient and left them feeling anxious and unsure of how to cope with ensuring the safety of their child. In addition, they identified inconsistent medical information as one of the major barriers to coping. The second study was New Zealand-based and involved in-depth interviews with four parents of children with severe food allergies (McBride, McBride-Henry et al. 2010). These parents revealed they had at times received inappropriate, unhelpful, or contradictory medical advice and experienced difficulties accessing information about how to manage the allergen-free diet of their child. In addition, they found it difficult to access appropriate healthcare both prior to and after diagnosis of their child.

2.2.3.4 Costs of having a food allergy

The results of qualitative research show that the cost of allergen-free food products is an issue, although some individuals avoided extra financial cost by restricting their choice of foods (Sverker, Hensing et al. 2005, Voordouw, Cornelisse-Vermaat et al. 2009). Quantitative research comparing the costs of households with food allergy and households without food allergy did not reveal an increase in total cost of living (Voordouw, Fox et al. 2010). Voordouw, Fox et al. (2010) did identify significantly higher direct health care costs, indirect costs (lost time and lost earnings), and intangible costs (self-perceived health and well-being) among households with food allergy. These findings suggest that people with food allergies may be using strategies to avoid an increased financial burden, but are paying in other ways, such as loss of time, and reduced variety and enjoyment of food. Further research is required to evaluate whether the extra cost of allergen-free food products translates into increased grocery costs, to understand

the cost-cutting measures employed by people with food allergies to keep overall cost of living down, and to determine the impact of those cost-cutting measures on other aspects of quality of life.

2.2.3.5 Psychological/emotional issues

Individuals with food allergies experience embarrassment, anxiety about the safety of food, anxiety about social implications such as being considered fussy or being a bother, social isolation and exclusion, and emotional pressure related to constant vigilance (Sverker, Hensing et al. 2005, Marklund, Wilde-Larsson et al. 2007, Sverker, Ostlund et al. 2009, MacKenzie, Roberts et al. 2010, Leftwich, Barnett et al. 2011). For adults with food allergies this is evident in their health-related quality of life in terms of lowered scores for social functioning and vitality (Flokstra-De Blok, Dubois et al. 2010). The extra strain related to these psychological and emotional issues may have implications for the mental health of individuals with food allergies. In addition, these and other issues discussed in Sections 2.2.3.1 to 2.2.3.4 may contribute to them experiencing considerable stress. The effect of food allergy issues on the experience of stress among individuals with food allergies is discussed in Section 2.2.3.6.

2.2.3.6 Food allergy issues and stress

Marklund, Ahlstedt et al. (2007) suggested that while some of the issues faced by individuals with food allergies may only result in moderate levels of stress when considered separately, the daily accumulation of frustrations and demands could undermine quality of life and contribute to stress-related health issues. Stress has been shown to have an adverse effect on physical health. Chronic or prolonged stress results in consistently higher than normal levels of stress hormones (epinephrine, norepinephrine, and cortisol) in the body (Sapolsky 2004). High circulating levels of these stress hormones have been linked to an increased risk of infections (due to inhibition of the immune system), and long-term health effects such as cardiovascular disease, diabetes, and depression (Cacioppo, Berntson et al. 1998, Cohen, Janicki-Deverts et al. 2007). To understand the of risk short- and long-term stress-related health complications among individuals with food allergies, research is needed to determine if food allergy management is associated with higher daily stress. If food allergy management is linked with stress, a detailed understanding of the issues that contribute to chronic stress in

individuals with food allergies will aid the development of interventions to reduce this stress.

2.2.4 Limitations of available quality of life literature

The majority of published research on the quality of life of adults with food allergies has involved the use of health-related quality of life questionnaires (both generic and food allergy specific). Several of these publications described in detail the development and testing (e.g., validity, test-retest reliability) of health-related quality of life instruments while paying less attention to what issues are important for people with food allergies. In addition, while these quality of life questionnaires can give an indication of ‘how often’ and ‘how much’ of an impact different predetermined issues have, the information is inherently limited by the questions asked (i.e., can only measure what the questionnaire asks about). Standardised questionnaires also tend to be limited in their ability to glean contextual information, such as answering ‘how’ and ‘why’ (DunnGalvin and Hourihane 2009). Relying solely on predetermined quality of life questionnaires will limit novel findings (DunnGalvin and Hourihane 2009) which, particularly in an area of research that is still in its early stages, is important to consider.

Qualitative publications related to the quality of life and experiences of adults with food allergies are limited to four studies. As discussed in Section 2.2.2 these four studies focused on specific aspects of life with food allergies (e.g., eating out, food choice) and/or a sub-group of the food-allergic population (adults with peanut and tree nut allergy, and adults with coeliac disease). While interesting, the narrow scope of these studies means their results have limited application, and that the overall knowledge about the experiences of adults with food allergies is incomplete. The lack of comprehensive qualitative research in this field means that little is known about the range of issues experienced by adults with food allergies or the effect of their reactions to the experience of some issues on the experience of other issues. Knowledge of food allergy-related issues is largely based on the reported experiences of children and adolescents, and their parents. Further research is needed discover if adults with food allergies experience additional issues and to elucidate whether the issues reported by children and adolescents, and their parents are relevant to adults with food allergies.

The participants in much of the published research have been predominantly white (or of European ethnicity) (Nettleton, Woods et al. 2010, Sommer, MacKenzie et al. 2012), female (Primeau, Kagan et al. 2000, Goossens, Flokstra-de Blok et al. 2011) and/or middle to upper class (Primeau, Kagan et al. 2000). Several publications did not report the ethnicity or income of the participants (Primeau, Kagan et al. 2000, Sverker, Hensing et al. 2005, Roos, Karner et al. 2006, Flokstra-de Blok, van der Meulen et al. 2009, Goossens, Flokstra-de Blok et al. 2011, Leftwich, Barnett et al. 2011), both of which may be important influences on the experience of life with food allergies. Gender, age, culture, and social standing are known to influence an individual's perceptions and understanding of health and illness (Lyons and Chamberlain 2006). Thus, the ability to generalize the results to the overall population will be limited when data has been collected from a specific sub-group of the population. Culture and ethnicity are important in the perception of health; for example, some cultures see social contact or connectedness as integral to health and relate social isolation to stress and ill health (Lyons and Chamberlain 2006). People's perceptions of health are not limited to just their own body or experience, but will be a function of the way health is understood in the society in which they live and by their place within that society (Lyons and Chamberlain 2006). In the context of food allergies, it would therefore stand to reason that the experiences of an individual with a food allergy would be influenced by the knowledge and attitudes of the society in which they live. Keeping this in mind, it is important to consider that having a food allergy in New Zealand (in the context of the New Zealand health system and social norms) may be experienced quite differently from having a food allergy in other countries (e.g., the Netherlands, UK, and USA) where the majority of the published research originates from.

2.2.4.1 Limitations of food allergy research in New Zealand

In New Zealand, research in the area of food allergies and quality of life is limited to a single publication — a small qualitative study with the parents ($n = 4$) of food allergic children (McBride, McBride-Henry et al. 2010). The research by McBride, McBride-Henry et al. (2010) found disturbing results in terms of the lack of access to appropriate health care for people with food allergies in New Zealand. The parents interviewed described difficulties accessing support, lengthy waiting times for health care services, being given inappropriate, unhelpful, or contradictory advice, and limited provision of

information about food allergy management. In addition, the parents all expressed feelings of social isolation for the whole family and experienced an increased financial burden. The study by McBride, McBride-Henry et al. (2010) provides a good initial indication of the issues that are relevant to New Zealand individuals with food allergies and their families. However, as the research involved only a very small number of participants, these results alone cannot be used to represent the needs of those with food allergies as a whole. To implement strategies for the effective management of this health problem in New Zealand, good quality information about the needs of individuals with food allergies is required.

2.3 Conclusion

Food allergy is a global health concern that appears to be increasing in prevalence. The dietary and lifestyle changes associated with food allergy management, along with societal attitudes and understanding of food allergies can have a significant impact on the health-related quality of life of individuals with food allergies. Issues identified from published research to date are related to finding safe foods, participation in social activities, medical care, the costs of having a food allergy, and psychological/emotional issues. However, current knowledge about the experiences of individuals with food allergies is still limited, particularly in relation to adults with food allergies. There is a need for comprehensive qualitative research with a heterogeneous group of adults with food allergies to elicit a deeper understanding of the range of issues that impact the lives of this under-researched group. In addition, quantitative daily life research is needed to elucidate whether food allergy management is a source of chronic daily stress, as is suggested in published literature.

CHAPTER 3

STUDY 1: UNDERSTANDING LIFE WITH FOOD ALLERGIES

3.1 Introduction

Chapter 2 reviewed literature relevant to the understanding of food allergies and quality of life. From this review, a gap was evident requiring more quality information about the experiences and needs of New Zealand adults with food allergies. Study 1 was designed to fill this gap. The current chapter gives an overview of the approach and aims of Study 1 and summary of the relevant literature (background information) to aid the understanding of this study. A description of the methods and findings follows, along with a discussion of the implications of these findings in the context of current literature, and conclusions for Study 1.

3.1.1 Overview of Study 1

In this study, I used a transformative consumer research approach to understand the problems relevant to adults with food allergies. I used a qualitative method (focus groups) to access the experiences of adults with food allergies. My approach was to facilitate an open discussion within a diverse group of adults with food allergies (e.g., range of food allergies, symptoms, ages, socio-economic, and cultural backgrounds). This approach enabled the discussion of a range of ideas and perspectives. The purpose of this research was to gain an in-depth understanding of life with food allergies, to identify and better understand the issues that affect the lives of adults with food allergies, and to identify strategies to improve their quality of life. My aim was to explore the experiences of adults with food allergies and understand the implications of living with food allergies in terms of consumer vulnerability and health-related quality of life.

3.1.2 Background information

Food allergy is an important health problem that can significantly impair quality of life (Flokstra-de Blok, Dubois et al. 2010). Patients with food allergies 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, 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 allergy-causing substance” (Metcalf, Sampson et al. 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 et al. 2009, Sicherer 2011).

Food allergy treatment involves 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, Haskard-Zolnierek 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).

3.1.2.1 Consumer vulnerability

Transformative consumer research recognizes that the well-being 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, Pettigrew et al. 2011). 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, Gentry et al. 2005). For example, an individual who is unable to achieve their consumption goals due to circumstances beyond their control will experience consumer vulnerability. The model of consumer vulnerability developed by Baker, Gentry et al. (2005) shows how individual characteristics, individual states, and external conditions each contribute to the experience of consumer vulnerability.

Consumers with food allergies are likely to experience heightened consumer vulnerability because of their food allergy and society's response to their food allergy. By understanding the experiences of adults with food allergies, it will be possible to learn if consumer vulnerability is in fact experienced and how this can be addressed to improve the well-being of this group of consumers. Such information can be used by consumers with food allergies, support groups, policy makers, food businesses (e.g., food manufacturers, cafés and restaurants), and other interested parties to improve the well-being of consumers with food allergies. Insight into the perspectives and experiences of consumers with food allergies will foster a better understanding and a greater ability to empathize among individuals without food allergies (including health professionals, food service providers, and the general population). In addition, other consumers with food allergies 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.

3.1.2.2 Health-related quality of life

Management of food allergies is challenging and has been shown to significantly impair health-related quality of life (Sicherer, Noone et al. 2001, Marklund, Ahlstedt et al. 2006, Östblom, Egmar et al. 2008, Flokstra-de Blok, Dubois et al. 2010). 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. Research comparing individuals with food allergies to those with other chronic health conditions found the health-related quality of life of individuals with food allergies was poorer than that 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 individuals with food allergies are faced with social barriers that prevent them from participating fully in society (Pitchforth, Weaver 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. In addition, patients with food allergies engage more health care services than patients

without food allergies, resulting in an increased cost to the health care system (Patel, Holdford et al. 2011). Thus, the development of interventions to improve quality of life will not only benefit individuals with food allergies 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 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 and 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 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 children with food allergies (DunnGalvin, Gaffney et al. 2009, Fenton, Elliott et al. 2011, Pitchforth, Weaver et al. 2011) and adolescents (Akeson, Worth et al. 2007, MacKenzie, Roberts et al. 2010, Marklund, Wilde-Larsson et al. 2007, Olsson, Lyon et al. 2009) or explored the perspectives of their parents (Gillespie, Woodgate et al. 2007, Mandell, Curtis et al. 2005, McBride, McBride-Henry et al. 2010). Qualitative research that addresses quality of life issues in adults with food allergies 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, such as eating out or food product labelling (Leftwich, Barnett et al. 2011, Nettleton, Woods et al. 2010, Sverker, Hensing et al. 2005, Voordouw, Cornelisse-Vermaat 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 adults with food allergies allows for deeper insight to gain a better understanding of what life with food allergies is like. Such information will facilitate the development of clinically significant interventions.

3.2 Methods

3.2.1 Methodological approach

As a researcher, it is important to be aware of any beliefs or philosophical assumptions that inform and guide my approach to research. The way we conduct research is influenced by how we view reality (our ontological standpoint) and how we view knowledge (our epistemological standpoint). I approached the design and implementation of Study 1 from an interpretivist perspective, meaning that reality is subjective and knowledge is socially constructed (Saks and Allsop 2007). This perspective focuses on the understandings of the research participants and involves figuring out the meaning of participants' experiences from their perspective (Saks and Allsop 2007). Qualitative methods that are consistent with the interpretivist perspective include methods such as in-depth interviews, focus groups, and ethnographic observation because they produce data that allows the researcher to seek understanding of individual experiences and identify patterns in those experiences. Validity and reliability of data, from an interpretivist perspective, relates to the degree to which the data accurately represents the sample population's attitudes, perceptions, and truths (Saks and Allsop 2007). According to Cohen and Crabtree (2008), the goal of qualitative research from this perspective is to understand and provide a meaningful account of the perspectives studied. For this reason, I report the findings with a strong focus on the participants' perspectives in their own words (using detailed quotes).

3.2.2 Study design and recruitment

I used focus groups to generate data in this qualitative study to capture a range of perspectives from the target group (adults with food allergies). In addition, focus groups were chosen because focus group participants are 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 enables the identification of issues that previous research might not have examined. To facilitate the collection of novel information, I chose to use a nondirective approach for the focus groups, allowing the participants' views to emerge spontaneously through open discussion within the group.

Participant recruitment involved convenience sampling by advertising for volunteers on community notice boards and through allergy support organizations. I believed this sampling method was appropriate to the aim of recruiting a wide range of adults with food allergies. The participants in the focus groups were homogeneous groups in the sense that they shared the experience of having a food allergy, allowing a supportive environment for the discussion of issues. However, the groups were heterogeneous in terms of socio-demographic characteristics (e.g., gender, age, ethnicity) and specific food allergy characteristics (e.g., type of food allergy, symptom severity, time since diagnosis), allowing the discussion of a range of experiences and perspectives.

Individuals who were interested in participating contacted me via email or telephone and were provided with further details of the study, including a copy of the participant information sheet. They could also ask further questions about the study via email or telephone. To be included in the study, participants had to have a medically diagnosed food allergy to one or more foods (diagnosed by a GP doctor or allergy specialist doctor) and be available to attend a focus group session in Dunedin or Auckland. All participants self-reported a medically diagnosed food allergy.

Being new to facilitation of focus groups, I prepared for the role of facilitator by reading extensively about how to run focus groups. In addition, I discussed the approach I intended to take with experienced focus group facilitators and received detailed advice on how to facilitate the groups. An experienced focus group facilitator joined the first focus group to observe and provide feedback on how I facilitated the focus group.

3.2.3 Participants

The 29 focus group participants (6 men and 23 women) were aged 20–77 years (mean age 43.6 years). The sample included participants with a range of food allergies and symptoms (Table 3.1). Nine of the participants reported two or more food allergies.

Although most participants identified themselves as New Zealand European ($n = 21$), the sample also included participants who identified themselves as other European ($n = 3$), 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 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 level ($n = 3$).

Table 3.1 Summary of Study Participants' Food Allergy Details, $n = 29$

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

^a Other foods: tomato, pineapple, kiwifruit, spirulina, legumes, chicken, banana, goat & sheep milk.

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

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

3.2.4 Ethics

I obtained ethical approval from the Department of Food Science and Department of Psychology ethics committees (University of Otago, Dunedin, New Zealand) prior to commencement of the study (see Appendix B). As described in section 3.2.2, I provided the participants with detailed information about what would be involved and gave them the opportunity to ask questions before they signed up for a focus group time. Participants also received a copy of the participant information sheet at the start of the focus group prior to giving their written consent (see participant information sheet and consent form in Appendix C). With the participants' permission, the focus group sessions were audio and video-recorded and verbatim transcripts were prepared using the recordings. Participants each received a \$20 fuel voucher to compensate them for travel costs. As indicated on the participant information sheet and consent form, participants were given the opportunity to request to review their focus group transcripts, however, no participants chose to take up the opportunity.

3.2.5 Data collection

Prior to attending the focus group, participants each completed a short online survey to collect basic socio-demographic (e.g., age, gender, ethnicity, income, education) and food allergy information. 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 (using a free-text reply box). I used these issues to develop a list of ten statements about living with food allergies (Figure 3.1). This list of statements formed the basis of the introductory exercise that participants completed prior to the group discussion. To complete the introductory exercise, I asked participants to rate each of the statements in terms of their importance/level of impact on their lives. The purpose of the introductory exercise was to provide a starting point for the discussion that followed.

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 towards 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 3.1 Introductory exercise with ten statements about living with food allergies

Focus groups were held in Dunedin (seminar room at the Department of Food Science, University of Otago, $n = 2$) and Auckland (seminar room at a motel, $n = 1$; and seminar room at Allergy New Zealand Annual General Meeting, $n = 1$). I conducted focus groups lasting 90–150 minutes with four different groups of adults with food allergies (3–11 participants per group, total $N = 29$). The number of participants per group and the number of groups needed for a study are both important considerations

when conducting focus group research. In the current study, the smaller groups had the advantage of allowing all the participants the opportunity to discuss the issues in greater detail, while the larger groups elicited a greater range of experiences and opinions. The number of focus groups needed to meet the aims of the study was determined by applying saturation theory. Saturation is believed to have occurred when information from further focus groups does not generate new understanding of the research topic (Liamputtong 2011). Theoretical saturation usually occurs after three or four focus groups with one target group (Krueger and Casey 2001). In the current study, the information gathered from the fourth focus group elicited no new understanding (i.e., theoretical saturation was reached) therefore I did not conduct any further focus groups.

The focus group participants were involved in an in-depth discussion about the food allergy-related issues that affected their lives. I facilitated all four focus groups using a nondirective approach to allow the participants' views to emerge spontaneously. A copy of the facilitator's guide is included in Appendix A. I 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, I explained what my 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). I then revealed my 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 the idea of sharing their own experiences. My insider status also enhanced my ability to relate to and empathize with the focus group participants.

Although the aim of this study was to improve theoretical knowledge about quality of life for adults with food allergies, the primary driver for this research was to improve their quality of life by adding to the existing body of knowledge, allowing the identification of suitable interventions. For this reason, collaboration and trust between researcher and participants was important. To facilitate collaboration, I explained the overall end goal of the research to the participants at the start of the focus group. Reciprocity was also important for this research and I achieved this through participants sharing support and advice during the focus groups. For many participants, it was a first opportunity to share their experiences openly without feeling they were being bothersome. Several 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.

3.2.6 Data analysis

Thematic analysis (based on the six phase method described by Braun and Clarke 2006) of the focus group transcripts was completed using the NVivo 9 software package (QSR International 2010). While thematic coding is commonly considered a tool for use within other analytic traditions (e.g., grounded theory, discourse analysis), Braun and Clarke (2006) argue that it is a method in its own right as long as defined steps are followed and the theoretical position of the research is made clear. I used thematic analysis in the context of it being an independent method. I followed a semantic approach, organising the data to show patterns and interpreting the significance of patterns, the broader meanings, and implications.

I completed all the data coding and analysis (in consultation with my primary supervisor). My own food allergy allowed a unique insider perspective to the data analysis. However, I was also aware that a person's culture and the society in which they live, as well as their age, gender and socio-economic status could all strongly influence their perceptions in relation to illness and related experiences. This awareness enabled me to approach the data from an outsider's perspective as well. By being aware of my insider/outsider status, I was able to reflect on how this might influence my approach to the research and take measures to minimize the effects of potential disadvantages of each position while attempting to maximize the strengths (e.g., revealing my own food allergy to participants, and acknowledging that each individual can have different experiences).

The main aim of the thematic analysis was to provide a rich description of the entire data set. I used an inductive approach similar to grounded theory, identifying themes and coding the data while reading the transcripts. However, my prior awareness of issues related to living with food allergies assisted the coding process and my 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 sub-themes. I

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). Table 3.2 describes the steps I followed for the thematic analysis in more detail. As outlined in section 3.2.1, I examined the data from two different perspectives: consumer vulnerability and health-related quality of life. The consumer vulnerability approach focused more on the overall experiences of life with food allergies while the health-related quality of life approach focused more on the issues that affect the lives of adults with food allergies, and strategies to improve their quality of life.

Table 3.2 Steps followed in thematic analysis

Step	Description of process
1. Familiarise with the data	This step included the data collection (facilitation of focus groups) and transcription of the focus group recordings because these contribute to the knowledge and understanding of the data. I then further immersed myself in the data by actively reading and re-reading the transcripts while looking for patterns and meanings in the text.
2. Assign initial codes	I assigned code names that identified patterns in the data set. Using NVIVO, I selected sections of text while reading the transcript and named each selection with a code. I also included surrounding text that provided context. NVIVO then saved all sections of text with that code under the code name. Some sections of text were relevant to more than one code and therefore saved under each relevant code.
3. Search for themes	I sorted the initial codes into potential themes and sub-themes with the aid of a thematic map to visualise the relationships between codes/themes/sub-themes.
4. Review themes	I read the data for each theme to check for coherence and ensure that differences between themes were clear and identifiable. I recoded extracts that did not fit and checked that the resulting thematic map accurately reflected the data set as a whole.
5. Define and name themes	I defined themes and identified suitable names that would describe the essence of each theme.
6. Write-up	I wrote the findings to tell the story of the data.

3.3 Findings

3.3.1 Consumer vulnerability perspective

These findings tell the stories of the 29 adults with food allergies who participated in the focus groups. The participants shared their experiences with food allergies, including their journey to diagnosis, their reaction to the diagnosis, post-diagnosis adaptation, ongoing life with food allergies, and their experience of symptoms (the five main themes). I identified two further subthemes for ongoing life with food allergies: having food allergies has shaped my life path, and having food allergies restricts my life. A descriptive summary of the participants (with their assigned pseudonyms) has been included to aid the interpretation of these findings, including a representative quote from each participant (Table 3.3). These quotes were taken from the icebreaking exercise at the start of the focus groups, where each participant shared something positive about his/her life with food allergies. The 'something positive' quotes aid the understanding of who the participants were, and what was important to them.

Table 3.3 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."

Table 3.3 Characteristics of focus group participants, continued

Pseudonym	Male/ Female	Age	Food Allergies	Symptoms	'Something positive' quote
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), 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."
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."

Table 3.3 Characteristics of focus group participants, continued

Pseudonym	Male/ Female	Age	Food Allergies	Symptoms	'Something positive' quote
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."

3.3.1.1 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 7. 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."

3.3.1.2 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.

3.3.1.3 Adjustment to a new life

For those who had suffered severe symptoms and/or for long periods of time, the biggest initial post-diagnosis change was a positive one. Participants described a substantial 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 because 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."

3.3.1.4 Ongoing 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).

3.3.1.4.1 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.”

3.3.1.4.2 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 life with food allergies will be presented in the section titled ‘Factors that impact on health-related quality of life.’ In addition to discussing the

issues they faced in everyday life, the participants 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 two 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:

Tom: “That feeling of going through a supermarket and just going aisle after aisle and there’s nothing ...”

Lin: “Like you said, you go down the, go down the aisles and you, you basically come back out with an empty basket.”

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 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 . . .”

3.3.1.5 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 severe 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 the 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."

3.3.2 Health-related quality of life perspective

Key factors that impact on health-related quality of life were grouped into three main themes and seven subthemes: (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). I developed a conceptual model to represent the key issues and their interactions (Figure 3.2). As illustrated in Figure 3.2, I found the issues related to having a food allergy to be complex and highly interrelated.

3.3.2.1 Issues related to living with a food allergy

3.3.2.1.1 Allergen-free eating issues.

I 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), I 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 allergen-free food products. Participants discussed "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 was 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."

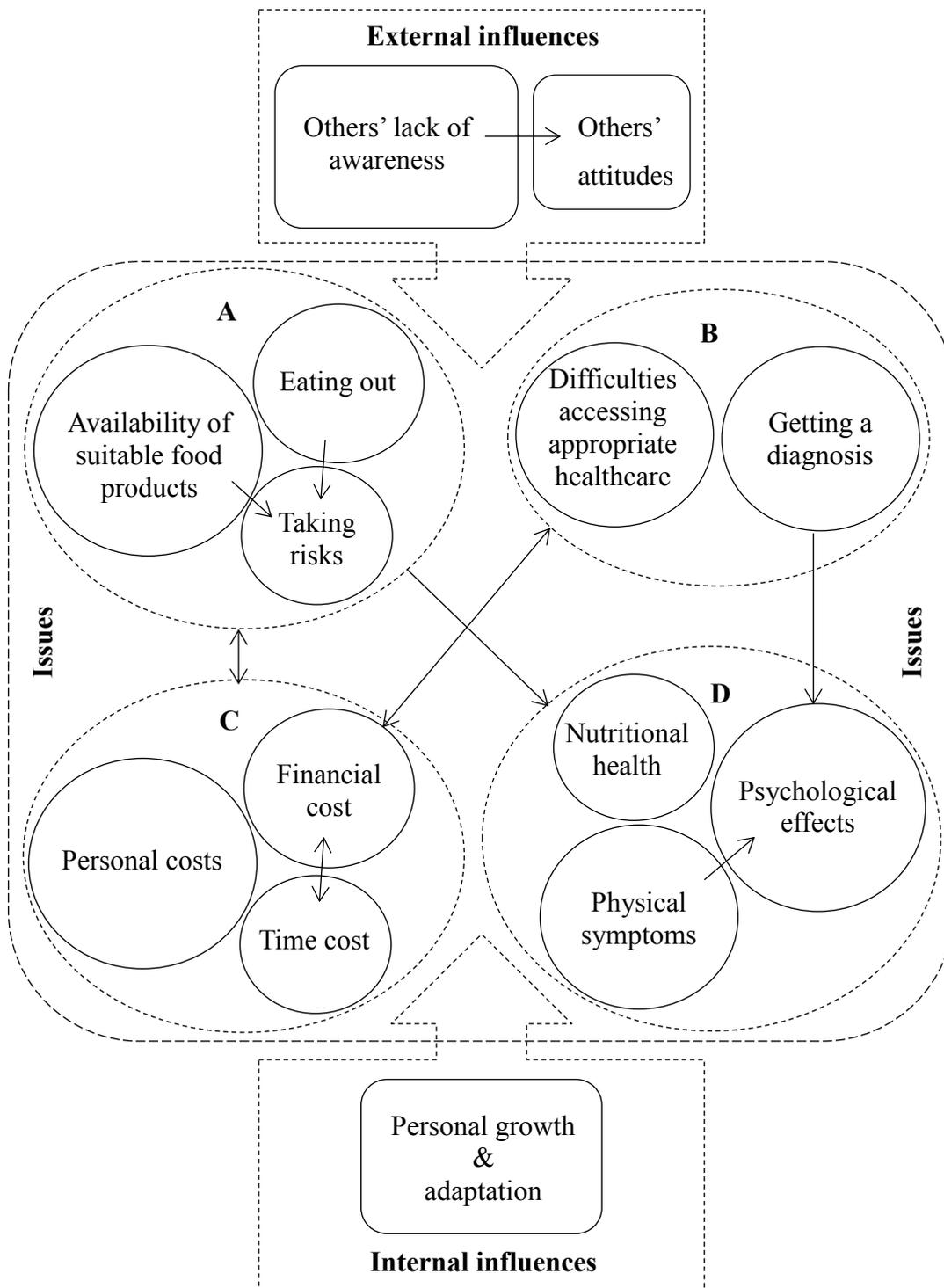


Figure 3.2 Overview of key themes and how they interrelate

A: Allergen-free eating issues; B: Healthcare system issues; C: Costs of having a food allergy; D: Effects on well-being. Arrows indicate the influence of one issue area on another (bi-directional arrows indicate both issues influence each other). Dotted lines indicate groupings of subthemes within different themes. Shape size reflects relative importance of subthemes.

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 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 flavour 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” labelling 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 or 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 their food allergen because it was too widespread in food products: “I mean, milk, it’s just in everything” and 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 adults with food allergies, as illustrated by the following statement by one of the participants as well as other quotes discussed later: “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, as participants described: “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 that 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 6 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.

3.3.2.1.2 *Health care system issues.*

I 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 lives. 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 of the participants: “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 18 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.” Participants explained: “I have to afford a trip to [location omitted] 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. For example, “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 anymore 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.”

3.3.2.1.3 *Costs of having a food allergy.*

I 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 lives:

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 ability to travel: “That really restricts, you know, where you can go.” One participant described avoiding international travel completely: “I’ve never even considered travelling, 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 omitted] and you would have the same thing. You do feel guilty but you can’t change it.” One participant with multiple food allergies felt: “It’s just as well I haven’t had kids, because I need to stop these genes right here.”

Everything costs more (financial costs) 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 non-funding 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 trade-off 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 pre-prepared 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.”

3.3.2.1.4 Effects on well-being.

I 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 [place omitted].” 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, for example: “I really worry about fibre. 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 where 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 afterhours 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 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 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.”

3.3.2.2 Factors that influence the perceived impact of food allergy and ability to cope

Both external influences (how others affect the food allergy experience) and internal influences (how the individual with food allergies can influence their own experience) have 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.

3.3.2.2.1 External influences.

I found two main external influences (a) others’ lack of awareness, and (b) 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 a food allergy. Low awareness among medical professionals such as general practitioners and dieticians 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 coeliac participant was referred to a dietician 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 coeliac participant shared her experience of going to see a dietician as disheartening because the dietician did not appear to understand her needs:

I was referred to a dietician, 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 dietician, 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. Participants discussed situations where restaurant or café staff lacked knowledge or awareness of food allergies, for example: "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 makes it more difficult to cope with allergen-free eating and food-related social occasions and can impact on physical and psychological well-being. Participants described examples where this lack of awareness was evident, for example: "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." Another participant explained:

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."

3.3.2.2.2 *Internal influences.*

Internal influences (personal growth and adaptation) affect how individuals with food allergies cope with the issues and therefore affect 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." Participants actively sought out 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. 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 lives.

The participants discussed the importance of being assertive: "I've got very good at talking to strangers in cafes and restaurants and explaining." Participants agreed that assertiveness was a necessary quality to keep them safe and to ensure others take 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.

3.4 Discussion

3.4.1 Consumer vulnerability

As outlined in Chapter 2 (section 2.1.2.2), the experience of consumer vulnerability affects subjective wellbeing because, if a consumer's consumption goals cannot be met, then that aspect of their life will not meet their expectations. From the findings presented above, it is evident that consumer vulnerability is likely to be experienced by consumers with food allergies, 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 consumers with food allergies. I 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 consumers with food allergies 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 severe 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, Gentry et al. (2005), individual characteristics, individual states, and external conditions contributed to the experience of vulnerability in these contexts. These factors will be discussed in more detail in the following paragraphs.

According to Baker, Gentry 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 participants in this 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 consumers with food allergies 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. I found that some consumers with food allergies 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 consumers with food allergies. Access to ongoing support and dietary advice would further facilitate this.

These findings indicate that consumers with food allergies 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, Gentry et al. 2005). External conditions that were important for the participants 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 consumers with food allergies and therefore present an opportunity for policy development and market changes that facilitate reestablishment of control to consumers with food allergies.

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 consumers with food allergies 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. Consumers with food allergies 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 consumers with food allergies to eat out with more confidence and without fear of stigma or discrimination.

3.4.2 Health-related quality of life

To my knowledge, this is the first comprehensive qualitative study investigating the range of issues impacting on quality of life of adults with food allergies. Although some of the issues discussed by the participants in this study have been noted in earlier

research articles (e.g., precautionary labelling restricting food choice (Voordouw, Cornelisse-Vermaat et al. 2009), difficulties with eating out (Leftwich, Barnett et al. 2011), risk-taking (Sverker, Hensing et al. 2005), and concern about accidental exposure (Flokstra-de Blok, van der Meulen et al. 2009, Sverker, Hensing et al. 2005)), this thesis adds further insight allowing a deeper understanding of these issues. For example, Voordouw, Cornelisse-Vermaat et al. (2009) discussed the burden of precautionary labelling, but did not explore how different adults with food allergies dealt with precautionary labels (i.e., whether they ignored them, or avoided them). My findings support the findings of Leftwich, Barnett et al. (2011) that different strategies (avoidance and communication) were used to manage risk in relation to eating out and that fear of social embarrassment was linked to increased risk-taking. Further, my results confirm that many of the challenges and strategies described by Leftwich, Barnett et al. (2011) apply to the wider food-allergic population, not just nut-allergic consumers. Sverker, Hensing et al. (2005) also reported disclosure avoidance and risk-taking among adults with coeliac disease but did not explore their participants' reasoning for this in detail. Moreover, in this thesis I explored the complex interrelationships between issues (Figure 3.2), which have not been discussed previously.

My findings add to the health-related quality of life data published by Goossens, Flokstra-de Blok et al. (2011) which was generated using the validated health-related quality of life measure for adults with food allergies developed by Flokstra-de Blok, van der Meulen et al. (2009). In agreement with my model (Figure 3.2), total scores for availability of suitable food products items and psychological effects items published by Goossens, Flokstra-de Blok et al. (2011) 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 behaviour; 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. Each of these issues were found to be important in the current study and several (e.g., loss of time, frequency/magnitude of symptoms, exposure to uninformed/misinformed people) are likely to impact on post-diagnosis health-related quality of life. These findings therefore indicate that the health-related quality of life measure developed by Flokstra-de Blok, van der Meulen et al.

(2009) lacks content validity, at least in the context of adults with food allergies living in New Zealand.

I found that the health care and food supply needs of patients with food allergies are currently not being met effectively. The specific issues related to health care and food supply are discussed in more detail in the following paragraphs. 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 well-being. The importance of having a clear diagnosis has been illustrated by van der Velde, Flokstra-de Blok et al. (2012) who found that health-related quality of life improved both after diagnosis of food allergy or ruling out food allergy using double-blind placebo-controlled food challenges. Based on the results of my research, there is a need for more trained allergy specialists in New Zealand to ensure food allergies are diagnosed in a timely manner. However, it is evident that this problem is not just specific to New Zealand. Agache, Ryan et al. (2013) identified access to allergy specialists as the greatest “unmet need” in allergy care across Europe, with average waiting times to see an allergy specialist of more than 6 weeks. In addition, 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 (i.e., general practitioners) has shown their knowledge and confidence in the area of food allergy diagnosis is insufficient (Gupta, Springston 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 (e.g., physical symptoms, psychological well-being, and financial cost of multiple doctor visits). Limitations of the available diagnostic methods can also make food allergy difficult to diagnose, particularly in the case of non-IgE-mediated food allergies (Sicherer 2011, Skypala and Venter 2009). Development of

better food allergy diagnostic methods such as those discussed by Caubet and Sampson (2012) would therefore be beneficial.

While the importance of knowledgeable nutritional/dietetic support in the management of food allergies has been recognised in published literature (Skypala 2011), this support may not always be available to individuals diagnosed with food allergies. In the experience of the participants in this study, the advice of dieticians was not always helpful and on one occasion, misinformed. Other participants mentioned that dietetic support was not offered to them as an option. Advice from a dietician who is experienced and knowledgeable in the area of food allergies would be highly beneficial to patients newly diagnosed with food allergies. It would be helpful if dieticians involved in caring for patients with food allergies received specialized training to have a thorough understanding of realistic and appetizing alternatives to allergen containing foods.

My findings highlight the importance of patient-centred care. Patient-centred care means the experiences and preferences of the patient, scientific evidence, and practitioner knowledge all shape the provision of health care (Thille and Russell 2010). Patients with food allergies 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 patients with food allergies. In addition, well-informed medical professionals are more likely to recognise food allergy-related issues and will be better equipped to provide relevant and appropriate advice regarding management of their condition. As a result, patients with food allergies will feel supported and understood, promoting a better patient-practitioner relationship. A good patient-practitioner relationship and a supportive environment are important for encouraging treatment adherence in chronic conditions (Sabaté 2003, Martin, Haskard-Zolnierek et al. 2010). In the case of food allergies, this means adherence to the allergen-free diet, which can be particularly difficult for newly diagnosed patients. Adherence to the dietary changes is important to prevent further (sometimes life-threatening) allergic reactions.

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” labelling was one of the main issues identified as causing a lack of availability of suitable foods. This supports previously reported findings that precautionary labelling is a burden for those with food allergies (MacKenzie, Roberts et

al. 2010, Monks, Gowland et al. 2010, Voordouw, Cornelisse-Vermaat et al. 2009). In the current study, even adults with severe food allergies (i.e., anaphylaxis) admitted ignoring “may contain” labelling and therefore were putting themselves at risk. As discussed in the ‘consumer vulnerability’ section, 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 patients with food allergies 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 individuals with food allergies to make use of them. As most individuals with food allergies 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, Fox et al. 2010). In addition, individuals with food allergies 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 adults with food allergies find it difficult to fit the extra food preparation time into their already busy schedules. The increased time burden is therefore likely to be source of stress and an important factor in the health-related quality of life of adults with food allergies. In addition to dietary and lifestyle restrictions, the participants’ explanations of the trade-off between financial cost and time cost also help to explain the findings of Voordouw, Fox et al. (2010). Based on my results, it is likely that both time cost and financial cost measures such as those used by Voordouw, Fox et al. (2010) will provide lower than expected overall averages. I 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 travelling) 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, 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 only available in specialty stores. The nutritional quality of allergen-free food products is important because the risk of nutritional deficiencies is already increased for many food-allergic individuals, simply because they are required to omit certain food groups from their diet. The nutritional implications of allergen-free eating are a particular challenge for those who are required to avoid a food that normally contributes significantly to nutritional adequacy (e.g., wheat, gluten, milk) and/or are allergic to several foods (Venter and Meyer 2010).

The lack of awareness about food allergies among others (including medical professionals, food service providers, food industry, and the general public) had a negative impact on the quality of life issues discussed here. A lack of awareness and knowledge about food allergies among others has been reported previously, both from the perspective of those affected by food allergies (Leftwich, Barnett et al. 2011, Peniamina, Bremer et al. 2014) and via surveys assessing the food allergy knowledge of restaurant staff (Ahuja and Sicherer 2007, Ajala, Cruz et al. 2010), the general public (Agache, Ryan et al. 2013, Gupta, Kim et al. 2009), and primary care physicians (Gupta, Springston et al. 2010). An improved societal awareness of what food allergies are and how they impact quality of life would not only improve practical aspects of food allergy management (e.g., faster diagnosis, improved access to suitable food), it would reduce the likelihood of stigma and social exclusion.

Published research has shown that children/adolescents with food allergies feel isolated or excluded because of the actions/comments of uninformed or misinformed people (Fenton, Elliott et al. 2011, MacKenzie, Roberts et al. 2010). I found that this also applies to adults with food allergies. 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 patients experience life with food allergies both prior to and after getting a diagnosis. An intervention addressing this lack of

awareness is likely to improve quality of life issues (especially risk-taking, personal costs, effects on well-being, and difficulties getting a diagnosis). Any such educational intervention should focus on the perspectives of patients with food allergies in addition to a clinical description of food allergy.

Keeping in mind the aim of identifying strategies to improve quality of life, individual qualities that aid coping and adaptation were an important dimension of this research. The main qualities seen as important for coping with allergen-free eating were assertiveness and organization skills. Interventions focusing on strengthening these skills in individuals with food allergies would improve their chances for successful adaptation to the management of their condition, therefore improving quality of life. Improved assertiveness would help individuals with food allergies to be able to ask for allergen-free foods and explain their needs to others, thus reducing risk-taking behaviour that would otherwise increase the risk of more frequent allergic reactions. Organizational skills would enable them to manage their time more effectively, reducing the time burden.

3.4.3 Strengths and limitations

The use of focus groups for data collection was a strength of this study because the group interaction allowed for the discussion of a range of experiences and perspectives, adding depth to the understanding of life with food allergies. The group context provided a safe environment for individuals to share their viewpoints about their food allergy-related needs. A limitation of focus group research is that it can sometimes be difficult to identify what was said (e.g., because of overlapping speech) and who said what (Liamputtong 2011). In the current study, the identification of who said what was aided by the use of video-recording. Maximum participation in the focus groups was aided by the group composition (i.e., homogeneous in terms of shared allergy-related experiences). This is because people who have similar lived experiences are more likely to feel comfortable to talk openly with each other (Liamputtong 2011). However, the composition of the focus groups was also heterogeneous because participants differed in age, gender, type of food allergies, and cultural backgrounds. This heterogeneity fitted with the goal of identifying a diverse range of perspectives and issues.

An additional strength of my study is the inclusion of adult participants from different age groups, ethnic 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; coeliac participants discussed problems with food texture; and participants on a budget avoided extra financial cost by spending more time sourcing and preparing foods. A limitation of using convenience sampling rather than purposive sampling for this study is that this meant a detailed comparison between different group variables (e.g., age, gender, time since diagnosis) was not possible. However, the purpose of the current study was to provide insight into the diverse range of experiences, views, and behaviours of adults with food allergies, rather than a detailed comparison of different sub-groups within the study population.

The advantages and limitations of thematic analysis are discussed in detail by Braun and Clarke (2006). An important advantage of thematic analysis is that this method is relatively easy to conduct well, even for those with limited experience in qualitative research. However, it is important to ensure that the interpretation of the data is consistent with the theoretical framework of the research, and that a rigorous approach is used. The main limitations of thematic analysis are that it is commonly misused, it is not widely recognized as a standalone method, and it has limited interpretive power if not used within a theoretical framework.

3.5 Conclusion

Consumer vulnerability is experienced by individuals with food allergies 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 chapter 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. In addition,

consumers with food allergies can gain strength from knowing that they are not alone in their experiences and gain insight as to how others adapt and cope.

These results also contribute to an improved understanding of the issues affecting the health-related quality of life of adults with food allergies. My findings will be useful to medical professionals to inform their patient-centred care. I 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 individuals who do not have food allergies (particularly general practitioners, dieticians, and food service providers), (b) assessing the quality of life of patients with food allergies 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 labelling). 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. My results also indicate that in many respects different food-allergic groups (e.g., IgE-mediated food allergy, coeliac) have the same needs. It would therefore be beneficial to consider them together as one group (i.e., “food allergic” as defined in Chapter 1).

Study 1 has provided an insight into the experiences, views, and behaviours of adults with food allergies; however, the generalizability of these findings needs to be assessed using quantitative methods. In addition, quantitative data will substantiate the need for the policy changes I have suggested based on my findings. Further research should therefore quantitatively assess the frequency and impact of the issues identified in this qualitative study. Study 2 (Chapter 4) will address this need for quantitative data.

CHAPTER 4

STUDY 2: THE STRESS OF FOOD ALLERGY ISSUES IN DAILY LIFE

4.1 Introduction

Study 2 is a quantitative extension of the previous study. This research draws on the allergy issues identified qualitatively in Study 1 to quantify the frequency and impact of these issues on people's functioning in daily life. This chapter will give an overview of the approach and summary of the literature relevant to Study 2 (background information). This is followed by a description of the methods and results, implications, and conclusions.

4.1.1 Overview of Study 2

Study 2 used the key allergy issues identified in Study 1 to investigate the patient-reported frequency of these issues and their impact on daily functioning (stress, mood, and physical energy) using daily survey methods. Each day for 14 days, participants with food allergies reported on the key food allergy issues they experienced that day, as well as their daily stress, mood, and physical energy using an Internet-based daily diary survey. The main aim of this study was to quantify the most common food allergy issues that people face in their daily lives, and to test the between-person and within-person relationships between the number of food allergy issues and experiences of stress, mood, and physical energy on a daily basis. Between-person relationships showed whether people who experienced more food allergy issues also experienced more stress, poorer mood, and less energy, on average. Within-person relationships showed whether individuals experienced more stress, poorer mood, and less energy on days with more (vs. fewer) food allergy issues. The hypothesis was that food allergy issues occur frequently in the daily lives of adults with food allergies and contribute to impairments in daily stress, mood, and physical energy levels.

A secondary aim of this study was to assess whether patients' socio-demographic, food allergy, and personality characteristics moderated the frequency and impact of food

allergy issues. Socio-demographic and food allergy issues may affect how food allergies are experienced and therefore influence quality of life. For example, it was expected that individuals/families with a lower income might report more issues related to food and medical costs. In addition, because some food allergens are more commonly found in staple foods than others, the type of food allergy might influence stress related to allergen avoidance. Other socio-demographic and food allergy characteristics (e.g., age, gender, symptom severity, and number of food allergies) have each been linked to differences in reported quality of life (Flokstra-de Blok, van der Meulen et al. 2009, Flokstra-De Blok, Dubois et al. 2010, Goossens, Flokstra-de Blok et al. 2011, Hallert, Sandlund et al. 2003).

4.1.2 Background information

Quality of life research shows that people with food allergies are often frustrated with always having to be alert, having little control or choice when eating out, having lifestyle restrictions put on them, and experiencing recurring physical symptoms due to accidental ingestion of the food allergen (Goossens, Flokstra-de Blok et al. 2011, Leftwich, Barnett et al. 2011, Peniamina, Bremer et al. 2014). However, previous research has investigated these issues through cross-sectional surveys or qualitative interviews. The next step in this line of research is to track the actual occurrence of food allergy issues in the daily lives of individuals with food allergies and to assess the links between allergy issues and daily functioning.

Daily functioning can refer to changes in both physical and psychological states. While a strong body of knowledge exists on the effect of food allergies on physical states (i.e., physical symptoms of food allergy), less is known about how food allergies affect psychological states such as stress and mood. This presents a problem because, based on published literature, patients with food allergies are more likely to be troubled by frustration related to allergy management than physical symptoms of food allergy. Based on published qualitative and cross-sectional survey data, it has been suggested that daily frustrations resulting from food allergy management are a “constant” source of stress for patients with food allergies, which can undermine their quality of life (Cummings, Knibb et al. 2010, Marklund, Ahlstedt et al. 2007, Peniamina, Bremer et al. 2014). However, the frequency and perceived impact of food allergy management issues and their association with quality of life have not been investigated in the context of daily life. Although adults

living with food allergies may differ in the types of issues they experience (Peniamina, Bremer et al. 2014), experiencing these issues on a day-to-day basis may impact their daily quality of life through increased stress, poorer mood, and reduced physical energy. Stress and mood are key daily indicators of subjective well-being, which is important to individual quality of life (Glatzer, Camfield et al. 2015). Physical energy is a concept similar to vitality, which Flokstra-De Blok, Dubois et al. (2010) found was impaired in adults with food allergies.

Research to date had not assessed the naturalistic relationship between food allergy management and daily experiences of stress, mood, and energy over time in real-world settings. Although cross-sectional surveys and qualitative interviews such as those used in published food allergy research are an important starting point for understanding the psychological concomitants of living with food allergy issues, other approaches are needed to assess the naturally occurring relationships between patients' allergy experiences and their psychological states in daily life. This gap in knowledge on how food allergy affects daily stress and mood means it is currently not possible to determine if patients with food allergies are at risk of stress-related short-term and long-term health complications. Such data can only be obtained by tracking allergy issues and testing their associations with psychological sequelae over time across consecutive days (Mehl and Conner 2012, Shiffman, Stone et al. 2008, Stone, Shiffman et al. 2007).

Understanding how allergy issues are related to daily changes in quality of life – particularly stress and negative mood – is important given the personal and social costs of impairment in these states. Increased daily stress and/or negative mood resulting from food allergy management could have implications for short- and long-term health outcomes of people with food allergies. Continual activation of the body's stress response has been linked to an increased risk of infections (due to inhibition of the immune system), and the development of insulin resistance disorders, cardiovascular disease, and mental health problems such as anxiety or depression (Cacioppo, Berntson et al. 1998, Cohen, Janicki-Deverts et al. 2007). Stress hormones can trigger an immune system imbalance of helper T-cells (Th cells), with a decrease in Th1 response (important for fighting infections) and an increase in Th2 response (responsible for allergic reactions) (Elenkov 2002). This shift in Th1/Th2 balance has particularly strong implications for patients with food allergies.

Like stress, negative mood is associated with an increased circulation of stress hormones (van Eck, Berkhof et al. 1996). Therefore, individuals who experience frequent increases in negative mood because of food allergy issues will have a higher risk of stress-related health complications. In addition to their potential effects on long-term physical well-being, stress and mood are also important indicators of current mental well-being, an important aspect of quality of life. Physical energy is a concept similar to vitality (commonly included in health-related quality of life measures). Items that measure physical energy provide an indicator of physical functioning in daily life. In addition to the individual costs of food allergies, there may also be societal costs in terms of lost work productivity (Voordouw, Fox et al. 2010) and increased costs to the health care system due to more frequent engagement of health care services (Patel, Holdford et al. 2011).

Quantitative assessment of food allergy issues using a real-time data capture method also makes it possible to test whether demographic or personal factors modulate the daily experience of allergy issues and/or daily psychological reactivity to allergy issues. Knowledge about the influence of demographic factors such as location (rural vs. urban), gender, income, and age, and food allergy factors such as time since diagnosis, number of allergies, and type of food allergy on the experience of life with food allergies is useful to the overall understanding of food allergies and quality of life. In addition, such data will inform the development of suitable interventions.

Published research has not assessed the influence of personality on the daily experience of allergy issues and daily psychological reactivity to allergy issues. Given that personality shapes the perception, interpretation, and behaviour of individuals in relation to their experiences (John, Naumann et al. 2008), it is likely that personality modulates the food allergy experience. For example, neuroticism could exacerbate the negative impact of allergy issues because neuroticism is associated with a disposition to experience greater stress-reactivity and poorer coping (Suls and Martin 2005). Conscientiousness predicts treatment adherence and better health habits because conscientious individuals are more likely to follow social norms and rules, think before they act, and delay gratification, and less likely to engage in risk-taking behaviours (John, Naumann et al. 2008). Behaviours such as planning, organizing, and prioritizing are a norm in conscientious individuals (John, Naumann et al. 2008), therefore it is possible that they will experience less impact from allergy issues on daily functioning. Extraverts

have a more energetic approach to life, experience more positive emotions, and are likely to be more sociable, active, and assertive (John, Naumann et al. 2008). Research has linked extraversion to positive health behaviours and better perceived health (Jerram and Coleman 1999). Individuals who are more open to experience will have broader, more complex lives and agreeable individuals are pro-social, community oriented, and tend to be modest, trusting, altruistic, and tender-minded (John, Naumann et al. 2008). Both agreeableness and openness to experience have been linked to positive health perceptions (Jerram and Coleman 1999).

4.2 Method

4.2.1 Study design

The current study used interval-contingent sampling, with data collection occurring once per day (i.e., daily diary study). Participants reported their experiences for each day at the end of the day (interval reports), for a period of two weeks. A two-week period was used for the daily surveys to allow for the experience of a broad range of issues (including two weekends) while keeping participant burden to a minimum. Internet surveys were chosen as the technology platform because of their high suitability for this type of data collection and their relatively low cost. In addition, the use of internet surveys (as opposed to paper surveys) allowed for control of the dates/times surveys were available to the participants. Based on similar studies of other specialised populations, it was estimated that a minimum of 80 participants would be required for this research.

4.2.2 Participant recruitment

Participants were recruited by placing advertising flyers at prominent locations (e.g., doctor's clinic noticeboards, supermarkets, libraries, universities, hospitals), through social media (advertising on Facebook), and by newspaper advertising (between January and July 2013). Individuals who had expressed an interest in the study during the initial recruitment period for Study 1 were contacted via email. Participants from Study 1 were also given the option to participate in this study.

Individuals who were interested in participating had the opportunity to ask questions via email, telephone, or using the study Facebook page. They could also go directly to the study website where they were provided with information about the study. To sign up for the study, participants were directed to click on a link, which took them to the screening questions (“Have you been diagnosed with a food allergy by a GP doctor or allergy specialist doctor?”, “Are you 18 years of age or older?”, and “Do you live in New Zealand?”). Individuals who answered “no” to any of the screening questions were given the message “Sorry you are not eligible to participate in this study.” Individuals who answered “yes” to all the questions were given the message “You are eligible to participate in this study. Click here to continue.” Eligible participants were then taken to the page where they could read the information sheet, give informed consent, and complete study registration.

As in the previous study, food allergy was defined as a reproducible adverse reaction caused by an immune-mediated response to a food or food component. This definition is based on the World Health Organization definition of food allergy, and includes both IgE-mediated food allergies and non-IgE-mediated food allergies (e.g., coeliac disease) (World Health Organisation International Food Safety Authorities Network (INFOSAN) 2006). Participants aged 18 years or older were included in the study if they self-reported a medically diagnosed food allergy. Reported symptoms, doctor who made the diagnosis, and method/s of diagnosis were used to confirm if participants fit the inclusion criteria for food allergy diagnosis. This study was approved by the Department of Food Science and Department of Psychology ethics committees (University of Otago, Dunedin, New Zealand) prior to commencement of the study. Informed consent was obtained from the participants prior to their participation (see participant information sheet in Appendix C).

4.2.3 Measures

The measures used in this study included an initial online survey followed by daily online surveys. The initial survey was designed to collect basic socio-demographic information and information about the participants’ food allergies (e.g., type of allergy; time since diagnosis). The initial survey also incorporated the Big Five Inventory (BFI) to collect information about the participants’ personality traits (John, Donahue et al. 1991,

John, Naumann et al. 2008). The daily survey was designed to be administered online on a daily basis over a two-week period. In the first section of the daily survey, participants were asked to rate their stress, mood, and physical energy in terms of how they felt “that day.” The stress measure was based on a single-item measure validated by Elo et al. (2003). Participants rated their stress that day on a 5-point scale from 1 (*not at all*) to 5 (*very much*). Negative mood items (irritable, anxious, sad), positive mood items (enthusiastic, happy, content), and physical energy items (energetic, run-down) were rated on a 5-point scale from 1 (*not at all*) to 5 (*extremely*), and averaged for each day (using reverse scoring for the “run-down” item). Reliabilities were .54 for the negative mood scale and .70 for the positive mood scale (multilevel reliability procedures based on Nezlek 2012).¹

In the second section of the daily survey, participants were asked whether they experienced any food allergy issues that day (yes/no). If yes, this was followed by a list of 25 food allergy issues (including “other”) for participants to select from. This list of food allergy issues was based on the results of the focus group research described in Chapter 3 (Understanding life with food allergies). The list included issues related to allergen-free eating, financial cost, time cost, personal cost, external influences, physical effects, psychological issues, and other. If participants selected “other” from the list, they were asked to explain briefly what other issue/s they experienced that day. The total number of issues per day for each participant served as a measure of their daily allergy issues and could range from 0 to 25. In the third section, participants were asked to select up to three issues that had the most impact on their life that day. Participants further rated each of these issues in terms of the perceived stress that it caused to them, and the perceived impact it had on their ability to complete normal daily tasks. A copy of the daily survey, including a complete list of the 25 issues can be found in Appendix D.

The online surveys were tested by the researcher and supervisors to ensure there were no technical problems prior to piloting the surveys using seven participants from Study 1. The participants in this initial group were asked to access the study website and

¹ Reliability values between .5 and .7 are common for three-item scales. Although more items would have increased reliability, a minimum number of items were chosen to keep the daily survey short. Reliability for the physical energy items was not computed because it was only a two-item scale; however, the items were highly correlated at the daily level ($B = -0.499$, $SE = 0.044$, $p < .001$).

complete the initial survey, followed by the daily surveys (each day for a period of two weeks). In addition, the participants were asked to provide feedback about the surveys (i.e., any issues they experienced with the surveys and/or comments about the survey content) via email. Technical issues that arose were dealt with prior to starting the main recruitment period. No problems were identified with the survey questions therefore the survey was not altered. This meant that the data from the pilot group could be included in the main analyses.

Both the initial survey and the daily survey were presented in sections, with the option to save and continue at the end of each section. Participants were not able to continue to the next section unless all required questions were completed. Backtracking (returning to previously completed sections) was not permitted once a new section had been accessed. The initial survey could only be completed once by each registered user (identified by their email address). Access to the daily survey was reset on each day. Participants were not able to complete the daily survey more than once on the same day.

4.2.4 Data collection

Participants accessed the study from a website self-hosted in the Department of Psychology on a secure VMWare virtual Windows 2008 server. The data was stored using SQL server 2008. After answering several eligibility questions (about allergy diagnosis, age, and availability) and giving informed consent, they were asked to complete the initial online survey prior to signing up for a two-week period during which daily surveys would be completed. Participants were given options of several upcoming two-week periods, all of which started on a Monday. They were then asked to complete the daily survey each day, which was accessible between 6 pm – 2 am during their chosen two-week period. A reminder email was sent out on the day of the first daily survey, and text reminders were sent out each evening during the two-week period. The data were collected between January and July 2013. Participants were entered in a prize draw (one prize of NZ\$200 and eight prizes of NZ\$100) as a thank you for their participation and were given the option to receive an individualized report of the study results.

4.2.5 *Statistical analysis*

Descriptive analyses were conducted on the allergy issues checklist to determine the frequency of allergy related issues, including the number and type of issues experienced, and the proportion of participants affected. Perceived stress and impact ratings were also examined descriptively to determine which issues were perceived as high stress and/or impact. Additional analyses were conducted to assess the influence of socio-demographic, food allergy, and personality characteristics on the experience of food allergy issues. Independent sample t-tests tested whether the experience of allergy issues (average number of issues per day and frequency of reporting for specific issues) differed between participant subgroups (participants living in small towns/rural locations vs participants living in larger cities, and male vs female participants). Pearson correlations tested whether the experience of allergy issues (average number of issues per day and frequency of reporting for specific issues) differed based on income level, time since diagnosis, and personality traits.

Multilevel modelling was conducted to determine the between- and within-person relationships between the number of food allergy issues and reports of daily stress, mood, and physical energy. Between-person multilevel models tested whether people who experienced more food allergy issues on average also experienced more stress, poorer mood, and less energy on average. The average number of allergy issues served as the level-2 predictor (grand-centred) and stress served as the level-1 outcome. Separate models were run for negative mood, positive mood, and physical energy as the other outcomes.

Within-person multilevel models tested whether individuals experienced more stress, poorer mood, and less energy on days with more (vs fewer) food allergy issues (within-person relationships). Stress served as the level-1 outcome and the number of allergy issues served as the level-1 predictor (group centred). Separate models were run for negative mood, positive mood, and physical energy as the other outcomes. Additional analyses were conducted to determine whether level-2 predictors (age, gender, income level, symptom severity, number of food allergies, type of food allergy, and personality) moderated the associations between number of allergy issues per day and the outcomes (stress, negative mood, positive mood, and physical energy). Multilevel models were run

using the Hierarchical Linear Modelling program (HLM 7 student version; Raudenbush, Bryk et al. 2011). More details about the multilevel models can be found in Appendix E.

4.3 Results

4.3.1 Participants

A total of 131 participants started the study. Of these, one was excluded because he/she did not fit the inclusion criteria (did not fit the criteria for food allergy diagnosis) and 22 were excluded because they completed fewer than five daily surveys. The data inclusion cut-off was set at 30% of daily surveys (a minimum of five out of 14 possible surveys) because this would allow enough data for the calculation of within-person association. The majority of excluded participants did not complete any daily surveys ($n = 12$) or completed only one daily survey ($n = 5$). Excluded individuals did not differ from included individuals on any of the study variables (socio-demographic and food allergy characteristics). The remaining 108 participants (15% male, 85% female) completed at least five (range 5 to 14) daily surveys during the two-week period. The included participants completed daily surveys on 76% of possible reporting days, on average (i.e., total number of surveys completed = 1144, total number of possible reporting days = 1512).

The included participants' mean age was 40.2 (range 18 to 87). Socio-demographic information (ethnicity, relationship status, type of household, income, education) about the participants is shown in Table 4.1 and food allergy information (food allergy type, symptoms, diagnostic methods used, doctors involved in diagnosis) about the participants is shown in Table 4.2. The sample included participants with a range of food allergies and symptoms. Several participants ($n = 19$) reported allergies to three or more foods. Most of the participants ($n = 79$) were diagnosed using a combination of at least two methods. Ten of the participants diagnosed using only one method had biopsy-diagnosed coeliac disease.

Table 4.1 Socio-demographic information of the study participants

Characteristic	n (%)
Ethnicity	
NZ European	92
Māori	11
Other European	12
Other ^a	7
Type of household	
Couple, no children at home	36
Family with children at home	33
Single parent with children at home	8
Group of adults (shared accommodation)	22
Adult living alone	6
Other ^b	3
Income (NZ\$)	
≤ 25,000	24
25,001-40,000	8
40,001-60,000	20
60,001-80,000	18
80,001-100,000	11
100,001-150,000	15
> 150,000	12
Education (highest qualification)	
High school	19
Polytechnic certificate or diploma	15
Trade qualification	3
Bachelor's degree	41
Postgraduate diploma	12
Masters or PhD degree	18

^aOther ethnicities: Indian, South American, Native American, African American, Australian, Canadian, American. ^bOther households: temporarily staying with parents, couple living with adult child and partner, hall of residence.

Table 4.2 Food allergy information of the study participants

Characteristic	n (%)
Type of food	
Gluten	59
Peanut	23
Cow's milk	18
Shellfish/seafood	18
Treenut	17
Egg	14
Fruit/vegetables ^a	12
Wheat	11
Soya	8
Other ^b	10
Number of foods	
1	68
2	21
3 or more	19
Type of symptoms	
Anaphylaxis	26
Gastrointestinal	85
Respiratory	32
Skin	58
Other ^c	30
Method/s used in diagnosis	
Blood tests	71
Biopsy	44
Skin prick testing	34
Medical history	34
Elimination diet/food challenge	29
Anaphylactic reaction after eating allergen	3
Allergy diagnosed by	
Gastroenterologist	41
General practitioner	37
Allergy specialist/immunologist	28
Other specialist ^d	2

^aFruit/vegetables: avocado ($n = 5$), kiwifruit ($n = 4$), banana ($n = 3$), tomato ($n = 2$), citrus fruit, lychee, tamarillo, pineapple, capsicum, corn, carrot, spinach. ^bOther foods: sesame ($n = 2$), chicken, beef, rice, broad beans, chickpeas, cocoa, peppermint, guar gum, spirulina. ^cOther symptoms: fatigue, headache/migraine, depression, dizziness, hotness/sweating, blurred vision, drowsiness, anxiety, confusion, lack of concentration, memory loss, oedema, oral allergy, mouth ulcers, anaemia, weight loss, leg pain, joint problems. ^dOther specialists: Dermatologist, specialist not specified.

4.3.2 Frequency and type of allergy issues

Participants experienced two food allergy issues per reported day on average (range 0 to 14; $M = 2.1$; $SD = 2.4$). Across the two-week reporting period, participants experienced issues on nearly 50% of reported days (range 0% to 100%, $M = 49.5\%$; $SD = 29.7\%$ of days). Some issues were reported more frequently and by a higher proportion of the participants than other issues. Table 4.3 shows a list of the top 10 issues experienced by a substantial proportion of participants. Issues were included in the top 10 if they were reported by 40% or more of the participants and/or they were reported on more than 10% of the total reporting days. The most common issues included those related to food choice (e.g., problems finding suitable foods, no food available), cost of allergen-free food, food allergy reactions (e.g., physical symptoms), and social activities (e.g., stress during social occasions). The mean perceived stress and perceived impact ratings showed that, on average, these commonly experienced issues were rated as moderately stressful ($M = 2.8$, range 2.2 to 3.0, $SD = 0.25$) and as having moderate impact on daily tasks ($M = 2.3$, range = 2.1 to 2.7, $SD = 0.20$). Of these top 10 issues, six issues were identified as particularly stressful for participants (marked with asterisk in Table 4.3), with the most stressful being extra financial cost (food).

Other less commonly experienced issues also had high ratings of perceived stress. For example, the highest perceived stress ($M = 3.5$) occurred with “people being uncooperative or unkind towards me because of my food allergy.” This also had the highest perceived impact on daily tasks ($M = 3.5$). However, only 7% of participants reported this issue, typically only once during the reporting period. In addition, “missing out on foods because of the cost of allergen-free products” had the second highest perceived stress ($M = 3.3$) and moderate perceived impact on daily tasks ($M = 2.8$). This issue was reported by 20% of participants, typically two or more times during the reporting period. Also worth noting are “lack of understanding from others in relation to my food allergy” (35% of participants, perceived stress $M = 3.1$, perceived impact $M = 2.6$), and “Feeling inadequate or defective as a result of my food allergy” (24% of participants, perceived stress $M = 3.1$, perceived impact $M = 2.7$). A complete list of all the issues and their perceived stress and impact ratings can be found in Appendix F (Table A-1).

Table 4.3 Proportion of participants affected, frequency reported, perceived stress experienced, and perceived impact on daily tasks for top ten issues

Issue	Proportion of participants (%) ^a	Frequency (%) ^b	Perceived stress (mean)	Perceived impact on daily tasks (mean)
Problems finding suitable foods to eat when away from home	65.7	15.3	2.5	2.1
Extra financial cost due to higher food prices for safe food*	63.0	17.0	3.0	2.3
Having to take risks by eating foods that may contain allergens	57.4	13.4	2.6	2.1
Loss of time due to extra time spent sourcing safe food	52.8	12.4	2.2	2.1
Physical symptoms of food allergy*	49.1	17.4	2.9	2.7
Feeling anxious about whether food is safe to eat*	48.1	11.8	2.9	2.3
Having to go hungry/not eat because there is no safe food available	46.3	9.7	2.7	2.6
Feeling anxious or stressed when participating in social occasions involving food*	41.7	7.9	2.9	2.3
Problems with finding suitable foods to purchase when grocery shopping*	39.8	5.7	2.9	2.3
Trouble with maintaining a healthy, nutritionally balanced diet as a result of my food allergy*	35.2	11.6	2.9	2.4

Note. The top ten issues were selected if they were reported by 40% or more of the participants and/or they were reported on more than 10% of the total reporting days. Issues identified as likely to cause moderate daily stress are marked with an asterisk.

^aProportion of participants: proportion of participants who selected this issue at least once during the reporting period. ^bFrequency %: percentage of reports in which issue was selected (reports with issue selected/total reports x 100).

4.3.3 Food allergy issues and daily functioning

Both between-person and within-person multilevel modelling analyses showed significant relationships between the daily number of reported food allergy issues and markers of daily functioning. Sections 4.3.3.1 (Between-Person Analysis) and 4.3.3.2 (Within-Person Analyses) present the findings related to these relationships.

4.3.3.1 Between-person analyses

Between-person multilevel models showed that participants who reported more daily food allergy issues also reported higher average daily stress ($B = 0.120$, $SE = 0.021$, $p < .001$), a more negative daily mood ($B = 0.063$, $SE = 0.017$, $p < .001$), and lower daily physical energy levels ($B = -0.080$, $SE = 0.018$, $p < .001$), but no differences in positive mood ($B = -0.034$, $SE = 0.026$, $p = .183$). Between-person variation in the number of food allergy issues explained 26.5% of the variance in average daily stress, 10.6% of the variance in average daily negative mood, and 10.3% of the variance in average daily physical energy.

4.3.3.2 Within-person analyses

Within-person multilevel regressions showed that on days that participants experienced more food allergy issues, they also reported higher stress ($B = 0.072$, $SE = 0.013$, $p < .001$) and a more negative mood ($B = 0.028$, $SE = 0.009$, $p = .002$). Daily stress was 0.072 points higher and negative mood was 0.028 points higher with each additional allergy issue experienced. Daily variation in the number of food allergy issues explained 4.5 % of the variance in daily stress and 3.5% of the variance in daily negative mood. These relationships were strictly linear, as testing for quadratic and cubic relationships found no significant relationships. Within-person multilevel regressions showed no linear or non-linear relationships between allergy issues and either positive mood ($B = 0.003$, $SE = 0.010$, $p = .800$) or physical energy ($B = -0.016$, $SE = 0.012$, $p = .178$).

However, age significantly moderated the associations between allergy issues and positive mood (age $B = -0.0018$, $SE = 0.0006$, $p = .004$) and physical energy (age $B = -0.0014$, $SE = 0.0007$, $p = .039$). Modelling these associations for people at age 70, 55, 40, 25 (corresponding to +2, +1, 0, and -1 SDs in age) showed that older adults were more

severely affected by allergy issues, with stronger reductions in positive affect (age 70, $B = -0.051$, $SE = 0.021$, $p = .017$; age 55, $B = -0.024$, $SE = 0.013$, $p = .076$; age 40, $B = 0.003$, $SE = 0.009$, $p = .709$; age 25, $B = 0.031$, $SE = 0.013$, $p = .019$) and greater decreases in energy (age 70, $B = -0.058$, $SE = 0.019$, $p = .002$; age 55, $B = -0.036$, $SE = 0.011$, $p = .002$; age 40, $B = -0.014$, $SE = 0.011$, $p = .203$; age 25, $B = 0.008$, $SE = 0.019$, $p = .687$) in response to allergy issues, relative to younger ages. Age did not moderate the within-person associations between allergy issues and stress ($B = -0.001$, $SE = 0.001$, $p = .548$) or negative mood ($B = 0.001$, $SE = 0.001$, $p = .087$).

Participants who reported allergies to three or more foods experienced reductions in positive affect ($B = -0.029$, $SE = 0.011$, $p = .010$) while participants with one ($B = 0.011$, $SE = 0.012$, $p = .384$) or two food allergies ($B = 0.007$, $SE = 0.032$, $p = .836$) did not. Number of food allergies did not moderate the within-person associations between allergy issues and stress, negative mood, or physical energy.

The type of food allergy participants had mostly did not matter. The one exception was that the relationship between number of allergy issues and stress was lower for participants who reported a shellfish or seafood allergy compared to participants with gluten or wheat allergy ($\chi^2 = 4.26$, $p = .037$). Data related to the influence of personality on the experience of food allergy issues is presented separately in section 4.3.5. No other demographic factors (gender, income level, symptom severity, location in New Zealand) moderated these within-person patterns.

4.3.4 Factors influencing the frequency and type of food allergy issues

Independent samples t-test results showed that adults with food allergies living in small towns or rural locations experienced more food allergy issues than those living in larger cities, on average (M town/rural = 2.8, M cities = 1.6, $p = .025$). In particular, participants living in small towns or rural locations more frequently reported problems finding suitable foods to eat when away from home ($p = .017$), problems finding suitable foods to purchase when grocery shopping ($p = .013$), having to go hungry/not eat because there is no safe food available ($p = .006$), trouble maintaining a healthy, nutritionally balanced diet ($p = .006$), extra financial cost due to medical expenses ($p = .025$), loss of time due to extra time spent preparing meals ($p = .020$) or organizing food ($p = .021$), avoiding participation in social occasions ($p = .026$), feeling anxious or stressed when participating in social occasions involving food ($p = .050$), difficulties travelling with

food allergies ($p = .047$), lack of understanding from others ($p = .021$), physical symptoms of food allergy ($p = .034$), feeling anxious about whether food is safe to eat ($p = .041$), and feeling inadequate or defective as a result of food allergy ($p = .042$).

No differences in reported number of issues per day were found between male and female participants ($p = .334$). However, a comparison of male and female participants' reporting of individual issues showed that female participants more frequently reported problems finding suitable foods to eat when away from home ($p = .005$), problems finding a restaurant or café that could provide an allergen-free meal ($p = .001$), trouble maintaining a healthy, nutritionally balanced diet ($p < .001$), people being uncooperative or unkind ($p = .012$), and feeling anxious about potentially having an allergic reaction ($p = .001$).

Lower income was not associated with differences in the number of allergy issues reported on average ($r = -.135$, $p = .163$). However, there were income differences in the types of issues experienced. Pearson correlations showed that lower income participants more frequently reported trouble maintaining a healthy, nutritionally balanced diet ($r = -.189$, $p = .050$), feeling anxious about whether food is safe to eat ($r = -.205$, $p = .033$), and feeling anxious about potentially having an allergic reaction ($r = -.255$, $p = .008$).

Time since diagnosis correlated with both number and type of issues experienced. A longer time since diagnosis was associated with fewer issues reported per day ($r = -.190$, $p = .049$). In particular, a longer time since diagnosis was associated with less frequent reports of having to take risks by eating foods that may contain allergens ($r = -.204$, $p = .034$), missing out on foods because of the cost of allergen-free products ($r = -.194$, $p = .045$), feeling anxious or stressed when participating in social occasions involving food ($r = -.206$, $p = .032$), lack of understanding from others ($r = -.192$, $p = .046$), and feeling anxious about "how people will react if I reveal my food allergy" ($r = -.251$, $p = .009$).

4.3.5 Influence of personality

The Big Five personality traits were associated with some differences in how participants experienced food allergy issues. The influence of each of the Big Five personality traits are discussed below.

4.3.5.1 Neuroticism

Contrary to predictions, there was no association between neuroticism and the number of daily reported allergy issues ($r = .079$, $p = .416$) or a higher frequency of specific issues. However, neuroticism significantly moderated the within-person association between allergy issues and negative mood (neuroticism $B = -0.019$, $SE = 0.008$, $p = .017$). Interestingly, people who scored higher in neuroticism had a weaker relationship between allergy issues and negative mood, a finding most likely due to higher overall negative mood as a function of neuroticism. Neuroticism did not moderate the within-person associations between allergy issues and stress ($B = 0.002$, $SE = 0.017$, $p = .908$), positive mood ($B = 0.021$, $SE = 0.015$, $p = .164$), or physical energy ($B = 0.015$, $SE = 0.016$, $p = .339$).

4.3.5.2 Openness

A higher openness score was associated with a higher reported number of allergy issues per day ($r = .235$, $p = .014$). In particular, a higher openness score was associated with more frequent reports of extra financial cost due to medical expenses ($r = .193$, $p = .045$), being excluded from social occasions ($r = .235$, $p = .015$), feeling anxious or stressed at social occasions involving food ($r = .261$, $p = .006$), lack of understanding from others ($r = .263$, $p = .006$), people being uncooperative or unkind ($r = .216$, $p = .024$), and feeling embarrassed ($r = .259$, $p = .007$). Openness did not moderate the within-person associations between number of allergy issues and reports of stress, mood, or physical energy.

4.3.5.3 Extraversion

Extraversion was not associated with the number of daily reported allergy issues ($r = .064$, $p = .510$). However, a higher extraversion score was associated with more frequent reports of specific issues: problems finding a restaurant or café that could provide an allergen-free meal ($r = .244$, $p = .011$), and people being uncooperative or unkind ($r = .220$, $p = .022$). Extraversion significantly moderated the within-person association between number of allergy issues and stress ($B_{extraversion} = -0.034$, $SE = 0.014$, $p = .020$) but not negative mood, positive mood, or physical energy. Participants

who scored higher in extraversion experienced less stress reactivity to allergy issues compared with participants who scored lower in extraversion.

4.3.5.4 Agreeableness

Agreeableness was not associated with the number of daily reported allergy issues ($r = .142, p = .143$), but a higher agreeableness score was associated with more frequent reports of feeling anxious or stressed at social occasions involving food ($r = .205, p = .033$). Agreeableness significantly moderated the within-person association between number of allergy issues and negative mood (B agreeableness = 0.031, $SE = 0.014, p = .030$) but not stress, positive mood, or physical energy. Participants who scored higher in agreeableness experienced more negative mood reactivity to allergy issues than participants who scored lower in agreeableness.

4.3.5.5 Conscientiousness

Conscientiousness was not associated with the number of daily reported allergy issues ($r = -.075, p = .443$), but a higher conscientiousness score was associated with more frequent reports of problems finding a restaurant or café that could provide an allergen-free meal ($r = .264, p = .006$) and less frequent reports of feeling embarrassed ($r = -.196, p = .042$). Conscientiousness significantly moderated the within-person association between number of allergy issues and positive mood (B conscientiousness = 0.063, $SE = 0.018, p = .001$) but not stress, negative mood, or physical energy. Participants who scored higher in conscientiousness were less likely to experience a decrease in positive mood in response to allergy issues than participants who scored lower in conscientiousness.

4.4 Discussion

This study confirmed that adults living with food allergies experience frequent allergy-related issues in daily life. Based on frequency, proportion of participants affected, perceived stress ratings, and perceived impact on daily tasks ratings (Table 4.3), the current study confirmed that key allergen-free eating issues (lack of suitable allergen-free food, risk-taking), cost issues (social limitations, financial cost of food, loss of time), and well-being issues (recurring physical symptoms, nutritional health, stress/anxiety)

identified from the qualitative research in Study 1 are important issues in the daily lives of adults with food allergies. The results also show evidence of food allergies influencing self-reported behaviour as 37% of the study participants reported avoiding social occasions because of their food allergy, at least once during the two-week reporting period (Table A-1, Appendix F). This type of behaviour, in combination with greater social exclusion because of food allergy (reported by 22% of participants) will lead to increased social isolation, which has been linked to poorer daily functioning (Hawkley, Preacher et al. 2010). Future research should further investigate the social implications of food allergies and their impact on daily functioning.

Some of the top issues identified quantitatively in the current study were similar to the top issues identified by Goossens, Flokstra-de Blok et al. (2011) using a validated food allergy quality of life questionnaire. For example, problems finding suitable foods, anxiety about safety of food, and anxiety/stress at social occasions were common to both studies. Constant alertness, vigilance, and labelling issues identified by Goossens, Flokstra-de Blok et al. (2011) are likely to contribute to the loss of time due to extra time spent sourcing safe food issue identified in the current study. However, the food allergy quality of life questionnaire used by Goossens, Flokstra-de Blok et al. (2011) did not include any questions about the effect of food allergy symptoms (only the fear of having a reaction and how discouraged they feel during a reaction), nor the cost of allergen-free food products, both of which were important issues in the current study.

Socio-demographic (location in New Zealand, gender, and income) and food allergy (time since diagnosis) factors were found to influence the frequency and/or type of food allergy issues experienced. It is likely that smaller and more remote locations have fewer specialist allergen-free products available, which could be why issues related to allergen-free eating were reported more frequently. Participants in smaller towns/rural locations are also less likely to have local access to medical professionals and support groups for food allergies, which could explain the more frequent reports of higher medical costs and social issues. Based on the results, the experience of food allergy issues is similar between male and female adults with food allergies, with the exception of five issues that were more frequently reported by female participants.

Surprisingly, income level was not associated with more frequent reports of financial cost issues. The more frequent reports of anxiety about safety of food and anxiety about potentially having an allergic reaction among lower income participants

may reflect a desire to avoid increased medical costs (i.e., appointments with doctor and/or purchase of medications such as epipens and/or antihistamines). The increased concern about nutrition may be related to cost-reducing strategies (avoiding the purchase of more expensive allergen-free products). The results also showed that adults with food allergies adapt over time, with a decrease in frequency of daily issues with increasing time since diagnosis. However, this decrease in frequency was only evident for two of the top ten issues, which further supports the need for interventions to address the top issues.

The frequency of food allergies also predicted poorer psychological functioning. At the between-person level, adults with food allergies who experienced more food allergy issues also experienced higher stress, a more negative mood, and lower physical energy. At the within-person level, adults with food allergies experienced greater stress and a worse negative mood on days with more food allergy issues. While correlational, these findings suggest that experiencing more food allergy issues has a negative impact on quality of life. In fact, between-person variation in reported allergy issues accounted for a large percentage of the variance in average stress (26.5 %), negative mood (10.6%), and energy (10.3 %). Moreover, the within-person relationships between food allergy issues and both stress and negative mood were linear, meaning that each increase in number of food allergy issues was linked with an increase in stress and negative mood that day. This suggests that reducing the frequency of food allergy issues could reduce daily stress and negative mood and therefore improve quality of life for adults with food allergies. These results support previous findings from cross-sectional research indicating a lower health-related quality of life and general well-being among individuals with a food allergy (Flokstra-De Blok, Dubois et al. 2010, Voordouw, Fox et al. 2010) and extend current knowledge by identifying key issues that may contribute to reduced subjective well-being in daily life.

Age moderated the within-person relationships between number of food allergy issues and both positive affect and physical energy, with older adults being more severely affected for these two outcomes. Interestingly, young adults showed a positive relationship between positive mood and food allergy issues. This could be because young adults are more likely to go out when they have a more positive mood and thus experience more allergy issues. These results indicate that approaches to help adults with

food allergies cope better with the management of their condition may need to be tailored differently for different age groups.

A possible explanation for the weaker relationship between daily stress and food allergy issues observed for participants with a shellfish/seafood allergy could be that participants with a shellfish/seafood allergy experienced fewer high stress issues than participants with gluten or wheat allergy. Shellfish/seafood is less likely to be an ingredient or potential cross-contaminant in processed staple food products compared to wheat or gluten. This means that higher stress issues such as problems finding suitable foods, having to take risks, cost of allergen-free foods, anxiety about safety of food, and physical symptoms of food allergy may have been less common among participants with a shellfish/seafood allergy compared to the participants with gluten or wheat allergy.

It is important to consider the influence of personality because personality traits can influence the way individuals interact with their environment and how they interpret meaning from their experiences (John, Naumann et al. 2008). Surprisingly, neuroticism was not associated with more allergy issues. Neuroticism slightly lowered the within-person association between allergy issues and negative mood, but it is likely that the higher baseline negative mood associated with a higher neuroticism score was responsible for this effect. It was not surprising that participants with a higher openness score were more likely to report more allergy issues (particularly social issues), as they were likely to be out experiencing more situations that would expose them to those issues. It also stands to reason that extraverted individuals, being more socially active, would go out to eat more often and therefore frequently experience problems finding a restaurant or café that could provide an allergen-free meal. Being naturally more social and going out more often would also result in more frequent exposure to people being uncooperative or unkind. However, while they may experience these two issues more often, there was no overall increase in number of issues per day associated with extraversion, and this personality trait was associated with lower stress reactivity to issues.

A higher score in agreeableness meant participants were more likely to feel anxious or stressed at social occasions involving food. This may be because participants with this socially conscious personality type did not want to upset anyone and therefore felt more anxious and/or stressed about having to assert their needs in a social setting. Anxiety about being bothersome to others may also explain the higher negative mood reactivity to allergy issues observed for these participants. The logical rule-following

approach of conscientious individuals could explain why they were less likely to feel embarrassed because of their food allergy (i.e., they feel justified in their behaviour because they are adhering to the rules associated with allergy management). Conversely, their desire to follow the rules and avoid risk-taking may also explain why they are more likely to report problems finding a restaurant or café that could provide an allergen-free meal.

Considering that the participants in this study experienced an average of two issues per day, it is possible that adults with food allergies are at risk of experiencing chronic elevated stress and negative mood. Given that both stress and negative mood have been linked to an increased circulation of stress hormones (Smyth, Ockenfels et al. 1998, van Eck, Berkhof et al. 1996), adults with food allergies may be at risk of long-term health complications. In addition, they also risk exacerbating their allergic reactions because stress has been linked to worsening of allergic reaction symptoms (Dave, Xiang et al. 2011, Wright, Cohen et al. 2005).

4.4.1 Strengths and limitations

The current research provides evidence of an association between allergy issues and daily stress and negative mood. Although these experiences were measured in “near to real-time” using a best-practice approach, this association is still correlational and does not prove a causal relationship. While it is likely that food allergy issues are contributing to daily stress and mood outcomes, it may also be argued that participants were more likely to report more issues if they felt stressed or were experiencing a more negative mood. Further research using an Ecological Momentary Assessment (EMA) approach to assess stress, mood, and number of issues experienced at set times during the day (e.g. morning, noon, and evening) or to assess stress and mood immediately after food allergy issues are experienced (i.e. event contingent sampling) is recommended to improve the understanding of the associations identified in the current study. However, the daily diary approach used in this research was a necessary first step to determine if associations exist between allergy issues and daily functioning. By using this approach, it was possible to test for associations between the experience of allergy issues and several aspects of daily functioning (e.g. stress, mood, physical energy), while also gaining an improved understanding of the frequency and type of issues experienced in daily life. The number

of questions required to achieve this meant EMA was not an appropriate method for this study. The current findings provide a basis for the development of an EMA study with fewer questions to minimise participant burden. Future research should also examine whether the observed difference in stress and mood on days with more food allergy issues is clinically significant. Such research would need to consider the cumulative effect of small rises in stress over consecutive days.

A further strength of this study was including adults with a physician-diagnosed allergy rather than a self-assessed allergy. However, this strict criterion made it difficult to recruit a larger number of participants for this research. Non-significant results found for gender comparisons may have occurred because of the low ratio of male to female participants who completed the study. It is therefore possible that gender differences were missed due to insufficient statistical power for a valid gender comparison. These issues are discussed in more detail in Chapter 5 (section 5.4).

Hierarchical Linear Modelling (HLM) analyses assume a normal distribution of the data and linear relationships between predictors and outcomes. However, testing was completed for quadratic and cubic relationships and found no significant relationships thus supporting the assumption that the identified relationships were linear. While HLM analyses take into account differences in the number of surveys submitted by different participants, the analyses assume that patterns of missing data (i.e. missed surveys) are random. It is possible, however, that missed surveys may represent days with more issues and higher stress (because participants are too busy or stressed to deal with surveys on those days) or days with no issues (because participants might be more likely to forget to complete a survey on days where no issues occurred).

Sample size affects the power of statistical tests. With multilevel models, it is important to consider the sample size for each level (Snijders 2005). In the current study the number of participants ($n = 108$) is the sample size for the level-2 data while the total number of daily reports ($n = 1144$) is the sample size for the level-1 data. The statistical power of a sample size of 108 participants should therefore be considered in the interpretation of between-person associations, while the sample size of 1144 daily reports should be considered in the interpretation of within-person associations. While a sample size of 108 participants may be viewed as a relatively low number, a study examining the issue of appropriate sample size in multilevel modelling found that bias only occurred with a level-2 sample size of 50 or less (Maas and Hox 2005).

The reliability values for the shortened three- and two-item scales used to measure daily negative mood, positive mood, and physical energy were less than ideal. However, the use of validated scales with more items would likely increase participant burden to an unacceptable level. Future research needs to address the need for short-item scales that are validated for use with daily diary and EMA research.

4.5 Conclusion

Participants in this sample experienced an average of two allergy related issues every day they were surveyed. Moreover, a clear link was identified between the number of food allergy issues and higher daily stress as well as a worse negative mood. Interventions targeting the prevention of issues should aim to reduce the number of allergy related issues people experience each day. Targeting the top issues could be accomplished by improving the cost and the availability of allergen-free food products, reducing the risk of accidental exposure, improving public understanding of food allergy, and providing access to nutritional advice with food allergy trained dieticians. Older adults experienced reductions in positive mood and physical energy on days with more food allergy issues, while younger adults did not. This suggests additional interventions tailored specifically for older adults may be useful. Personality traits influenced the experiences of adults with food allergies. People higher in openness and agreeableness, experienced more food allergy issues and increased negative mood reactivity, respectively. In contrast, people higher in extraversion and conscientiousness seemed buffered to the effects of food allergy issues (extraversion reduced stress reactivity and conscientiousness reduced the impact of allergy issues on positive mood). Based on these results, clinicians will be able to predict which patients are more likely to experience anxiety or stress, or have difficulty adapting to life with food allergies. Food allergies should be considered a growing health concern in the field of health psychology. The current findings indicate that the daily issues of living with a food allergy are frequent and detrimental to the psychological well-being of this growing population.

CHAPTER 5

GENERAL DISCUSSION AND CONCLUSIONS

5.1 Introduction

This chapter brings together the findings from Studies 1 and 2. Key findings are summarized and the implications and contributions of these findings are discussed. This is followed by a discussion of limitations of the current research, the main conclusions drawn from this thesis, and directions for future research. This chapter closes with a concluding statement of what the thesis has achieved in relation to the overall aims of the research.

5.2 Summary of key findings

Key findings from this thesis are summarized in Table 5.1, along with references to the section/s in the thesis where these were presented. The implications and contributions of these findings will be discussed in Section 5.3.

Table 5.1 Summary of key findings from this thesis.

Findings	Section/s of thesis where findings are presented
The road to diagnosis of food allergies can be long and difficult. <ul style="list-style-type: none">• Many general practitioners are not well-equipped to recognize and diagnose food allergies.• Access to allergy specialists is limited by a lack of available specialists and cost.	Sections 3.3.1.1 (The journey to diagnosis) and 3.3.2.1.2 (Health care system issues)
Some individuals will experience stages similar to grief/loss in response to diagnosis with a food allergy.	Section 3.3.1.2 (Reaction to diagnosis)
A clear diagnosis is important and aids the process of adaptation to required dietary and lifestyle changes.	Sections 3.3.1.2 (Reaction to diagnosis) and 3.3.2.1.2 (Health care system issues)

Table 5.1 Summary of key findings from this thesis, continued.

Findings	Section/s of thesis where findings are presented
A substantial improvement in health, information about allergen-free eating, and access to support from patient organizations make adjustment to the dietary and lifestyle changes easier.	Section 3.3.1.3 (Adjustment to a new life)
Difficulties in adjustment to the dietary and lifestyle changes result from having to reprogram food habits, missing out on favourite foods, and a lack of support to aid the transition process.	Section 3.3.1.3 (Adjustment to a new life)
Diagnosis with food allergies can have a positive influence on health behaviours, e.g., healthier food habits and reduced intake of alcohol.	Section 3.3.1.4.1 (Having food allergies has shaped my life path)
Widespread use of ‘may contain’ labelling restricts food availability and results in risk-taking.	Sections 3.3.1.4.2 (Having food allergies restricts my life) and 3.3.2.1.1 (Allergen-free eating issues)
The cost of allergen free specialty products further restricts food choice.	Sections 3.3.1.4.2 (Having food allergies restricts my life) and 3.3.2.1.1 (Allergen-free eating issues)
In addition to restricting food choice, having a food allergy limits ability to travel and restricts or reduces enjoyment of social activities (e.g., eating out).	Sections 3.3.1.4.2 (Having food allergies restricts my life) and 3.3.2.1.3 (Costs of having a food allergy)
The issues related to having a food allergy are complex and interrelated.	Section 3.3.2 (Health-related quality of life perspective)
Risk-taking occurs because widespread ‘may contain’ labelling unnecessarily restricts food choice, complete avoidance is too difficult or causes undesirable social restrictions, and because the enjoyment of certain foods is sometimes too tempting.	Section 3.3.2.1.1 (Allergen-free eating issues)
Treatment of food allergies (cost of food products and medical care) is expensive.	Sections 3.3.2.1.3 (Costs of having a food allergy) and 4.3.2 (Frequency and type of allergy issues)

Table 5.1 Summary of key findings from this thesis, continued.

Findings	Section/s of thesis where findings are presented
Those who cannot afford the extra cost of specialty food products will experience an increased time burden in sourcing and preparing foods.	Section 3.3.2.1.3 (Costs of having a food allergy)
Physical symptoms of food allergy occur regularly even when attempting to avoid allergens in the diet.	Sections 3.3.2.1.4 (Effects on well-being) and 4.3.2 (Frequency and type of allergy issues)
Dietary restrictions and a lack of readily available healthy alternatives cause concern about nutritional adequacy of the allergen-free diet.	Sections 3.3.2.1.4 (Effects on well-being)
Having a food allergy can result in increased stress and anxiety, and impaired self-image.	Sections 3.3.2.1.4 (Effects on well-being), 4.3.2 (Frequency and type of allergy issues), and 4.3.3 (Food allergy issues and daily functioning)
A lack of food allergy knowledge among medical professionals, food service staff, and the general public is commonly experienced and makes it more difficult for individuals with food allergies to cope.	Sections 3.3.2.2.1 (External influences) and 4.3.2 (Frequency and type of allergy issues)
Being proactive in learning about food allergy, and being more organized and assertive make it easier for individuals with food allergies to cope.	Sections 3.3.2.2.2 (Internal influences)
Food allergy issues are experienced frequently in daily life (average of two issues per day).	Section 4.3.2 (Frequency and type of allergy issues)
The food allergy issues that are the most important in daily life are related to problems finding suitable food, the cost of allergen-free food, nutritional concerns, physical symptoms of food allergy, anxiety about food safety, and stress/anxiety in social situations involving food.	Section 4.3.2 (Frequency and type of allergy issues)
Living in small towns/rural locations, being more recently diagnosed, and being more open to experience (personality trait) predict the experience of more food allergy issues.	Sections 4.3.4 (Factors influencing the frequency and type of food allergy issues) and 4.3.5.2 (Openness)

Table 5.1 Summary of key findings from this thesis, continued.

Findings	Section/s of thesis where findings are presented
Location (rural vs urban), gender, income, time since diagnosis, and personality influence the type of food allergy issues experienced.	Sections 4.3.4 (Factors influencing the frequency and type of food allergy issues) and 4.3.5 (Influence of personality)
<p>The experience of more food allergy issues in daily life is associated with increased stress and negative mood.</p> <ul style="list-style-type: none"> • Individuals who experience more food allergy issues are more likely to experience increased stress, a more negative mood, and lower physical energy (between-person analyses). • Individuals are more likely to experience increased stress and a more negative mood on days that they experience more food allergy issues (within-person analyses). 	Section 4.3.3 (Food allergy issues and daily functioning)
Older adults are more likely to experience reductions in positive mood and physical energy on days that they experience more food allergy issues.	Section 4.3.3.2 (Within-person analyses)
<p>Personality traits moderated the associations between food allergy issues and measures of daily functioning:</p> <ul style="list-style-type: none"> • Extraversion reduced stress reactivity to allergy issues. • Agreeableness increased negative mood reactivity to allergy issues. • Conscientiousness reduced positive mood reactivity to allergy issues. 	Section 4.3.5 (Influence of personality)
In the context of adults with food allergies, neuroticism did not predict greater reporting of issues, nor was it associated with higher stress- or negative mood-reactivity.	Section 4.3.5.1 (Neuroticism)

By combining methods, it was possible to gain a more detailed understanding of the issues that impact on the quality of life of adults with food allergies living in New Zealand and their relative importance. For example, Study 1 identified the range of issues that occurred in daily life from the experiences shared by the focus group participants and Study 2 added to this knowledge by determining the frequency and impact of these issues in daily life. Study 2 also confirmed the importance (in terms of frequency and impact) of several issues that the participants of Study 1 appeared to feel strongly about (e.g.,

difficulties finding suitable food, cost of allergen-free food, recurring physical symptoms, and anxiety about food safety, particularly in social situations involving food). The results of Study 2 also confirmed the impact of food allergies on psychological well-being discussed in the focus groups of Study 1, through both directly measured ratings (perceived impact) and identified associations between the experience of allergy issues and daily reports of stress and mood. Findings from Study 1 could also be used to explain and add a depth of understanding to the results of Study 2. For example, Study 2 showed that a lack of understanding from others was frequently experienced by the participants and Study 1 provided information about how participants felt about this lack of understanding, the context of where this lack of understanding was experienced, and how it interfered with their ability to cope with food allergy management.

Based on the findings discussed in this thesis, adaptation to life with food allergies is similar to other chronic illnesses. Bishop (2005, p. 219) describes the onset of chronic illness as “a life-changing event” that signifies the beginning of a “lifelong process of adaptation to significant physical, psychological, social, and environmental changes.” These changes can be experienced across multiple dimensions of an individual’s life and the response to these changes can vary significantly between individuals (Bishop 2005). A reduction in quality of life is experienced with the onset of chronic illness but, because people wish to maintain an optimal level of quality of life, adaptation occurs to close the gap between current and desired quality of life (Bishop 2005). Therefore, without adaptation the individual will continue to experience reduced quality of life. Adults with food allergies adapted to their changed circumstances by educating themselves about food allergies, becoming more organized, and becoming more assertive. Adaptation also involved attaching new, positive meanings to having a food allergy (e.g., focusing on benefits such as improved health consciousness and directions for career development).

Delgado (2007) discussed the impact of sense of coherence on quality of life in chronic illness. Sense of coherence can be defined as “a worldview that enables people to use resources effectively” (Delgado 2007, p. 229). An investigation of the relationship between sense of coherence and quality of life in patients with chronic obstructive pulmonary disease ($n = 181$, aged 30 – 87 years) found that participants with a strong sense of coherence reported better quality of life, regardless of symptom severity (Delgado 2007). A similar concept was evident in the current results with food-allergic adults. In focus groups, those who reported effective use of resources (e.g., accessing

information for self-education, accessing support networks) perceived a lower impact on quality of life compared to those who struggled to access resources. This could also explain some of the individual variation in perceived impact of food allergy issues.

5.3 Implications and contributions of the thesis

The implications of this thesis in the context of health behaviour theory are discussed in sections 5.3.1 and 5.3.2. The theoretical and methodological contributions of this thesis can be translated to clinical, policy, food industry, and advocacy implications. These contributions and implications are discussed in sections 5.3.3 to 5.3.8.

5.3.1 Implications in the context of Self-Efficacy Theory

From Study 1, it was apparent that self-efficacy traits such as self-education, assertiveness, organization skills, and accessing support from patient organizations aided food-allergic individuals to cope better with the task of food allergy management, which would reduce the perceived impact on quality of life. According to Hayden (2014, p.15), self-efficacy is “the belief in one’s ability to successfully accomplish something.” People with a strong sense of self-efficacy see difficult tasks as challenges rather than threats and approach difficult situations with confidence, which reduces stress and lowers the risk of depression (Hayden 2014).

Self-Efficacy Theory suggests four factors influence the perception of efficacy. The first factor is mastery experience and refers to the prior experience of success when attempting to do something (Hayden 2014). In the case of adults with food allergies, an individual may attempt to share information about their food allergy in an attempt to manage the risk of cross-contamination. If that attempt is met with success (i.e., the person they shared the knowledge with listened and used the knowledge to provide safe food for the food-allergic individual), that mastery experience would boost self-efficacy because that person will feel confident of similar success in similar situations in the future. This example shows how the actions of others could influence the confidence of an individual with food allergies in their own food allergy management skills, and thus their perception of stress and negative mood in relation to food allergy management. Another example is the experience of going out to eat at a restaurant. Participants who

had positive experiences with eating out in the past were more likely to keep going to restaurants, while participants who had more negative experiences were more likely to avoid eating out at restaurants because they perceived it as too stressful.

The second factor that influences the perception of efficacy is vicarious experience, or learning by watching someone similar to yourself successfully accomplish something you would like to do (Hayden 2014). Joining a patient organization support group could aid in this process as they provide an opportunity for food-allergic individuals to share their experiences of what food allergy management tactics worked for them in the past. In addition, this factor illustrates how the focus groups of Study 1 could achieve reciprocity by participants learning from the experiences shared by other participants. The importance of social support, in the form of friends, family, and support groups, is also evident from the third factor affecting efficacy, verbal or social persuasion. This factor infers that people are more likely to attempt something if others tell them that they can do it (Hayden 2014).

The fourth factor influencing efficacy is somatic and emotional states, which refers to the experience of states such as anxiety and stress in a new situation (Hayden 2014). People who experience strong negative somatic states are more likely to avoid situations that are associated with those feelings and, conversely, people who experience positive states are more likely to seek out situations or engage in the behaviour that created it (Hayden 2014). In this case, stress management training (e.g., cognitive-behavioural therapy, or mindfulness) would be useful to ensure an increased likelihood of self-efficacy in food-allergic adults.

5.3.2 Implications in the context of the Theory of Reasoned Action

According to the Theory of Reasoned Action, the likelihood that someone will engage in a behaviour (i.e., intention) is influenced by attitudes and subjective norms (DiClemente, Salazar et al. 2013, Hayden 2014). Attitudes are based on our beliefs and influence the value we put on a behaviour outcome (Hayden 2014). People are therefore less likely to engage in a behaviour if the perceived outcome of that behaviour is negative (Hayden 2014). This was observed in the context of food allergies, with participants reporting avoiding disclosure of their food allergies when they believed this would result in unfavourable social implications (e.g., being thought of as fussy or annoying) and

participants avoiding eating out because it was too stressful. Another example of this was evident in the behaviour of participants with less severe allergies who felt the advantages of adhering to strict dietary restrictions did not outweigh the disadvantages (e.g., too much time and effort for little benefit).

Subjective norms refer to the perceived social pressure to behave (or not behave) a certain way (Hayden 2014). Our behaviour is therefore influenced by our perception of what behaviour is expected of us by the people who are important to us (Hayden 2014), or in other words, we are motivated by our perceptions of what others find acceptable (DiClemente, Salazar et al. 2013). Examples of this from the current research include the perceived stigma and social embarrassment discussed by participants and the frequency of stress and/or anxiety in social situations involving food, sometimes resulting in avoidance of certain social situations. With this understanding of the effect of perceived social pressure on food allergy management, it is clear that community education about food allergies would have a positive effect on quality of life for food-allergic individuals. If people are perceived to understand about food allergies, food-allergic individuals will be less likely to experience stress, anxiety, and social embarrassment and more likely to engage in normal social interaction.

Hayden (2014) also discusses volitional control, which refers to whether someone has control over a behaviour. This is an important factor in food allergy management because having a food allergy results in a loss of control over food choices, and an inability to control the attitudes and behaviour of others in relation to providing safe food options. For example, individuals with food allergies intend to avoid allergens in their diet but frequently have to rely on others to provide safe food. This means that sometimes exposure to allergens in the diet can result from the mistakes of others (e.g., due lack of knowledge/ understanding of cross-contamination issues or what foods contain allergens). While they can make the choice to avoid eating anything in such situations, they are not in full control of whether the food they eat is allergen free if they choose to eat it. This means that, in some situations, good food allergen management relies on the attitudes and behaviour of others rather than the behaviour of the food-allergic individual.

5.3.3. Theoretical

This thesis contributes to an improved overall understanding of what life is like for adults with food allergies, both from a consumer vulnerability perspective and a health-related quality of life perspective. The results of Study 1 provide an insight into the experiences, views, and behaviours of adults with food allergies. This insight adds to and clarifies results of published quantitative research. The range of participants from different backgrounds and with different types of food allergies included in Study 1 made it possible to access a wider range of experiences and viewpoints compared to previously published qualitative research.

Study 2 is the first study to examine the frequency of food allergy issues and the implications of these issues for daily psychological functioning (stress and mood). The findings provide evidence that adults with food allergies experience allergy-related issues frequently in daily life. Important issues affecting quality of life were identified (based on the proportion of participants affected, the frequency of reporting, and the level of reported impact). In addition, this research provides evidence that the experience of allergy issues is linked to increases in stress and negative mood. The results of Study 2 also add to theoretical knowledge of how personality can influence illness experience and health behaviour.

5.3.4 Methodological

The use of a real-time method (daily surveys) in Study 2 is completely new in the food allergy research field. A new measure (the daily survey) was developed for this research, based on the findings of Study 1. This new measure can be used for similar future research investigating the impact of food allergy issues on daily life in different samples, such as adults with food allergies in other countries or adults with food allergies from specific target ethnic groups. The described methodology can also be followed to develop similar daily measures for children and adolescents living with food allergies. In addition, this research illustrates the benefits of mixed methods research, an underutilised approach in food allergy-related quality of life research to date. By combining qualitative and quantitative methods, it was possible to gain broader knowledge (i.e., answer questions about what, how, and why as well as how much and how often) about how food allergies impact quality of life.

5.3.5 Clinical

The findings from Study 1 highlight the importance of patient-centred care, where the perspectives of the patient are considered along with scientific evidence and practitioner knowledge to shape the provision of health care. These findings also provide valuable information on the experiences and perspectives of patients with food allergies that should be used to inform patient-centred care. A clear diagnosis is important for the well-being of patients with food allergies, but significant delays in diagnosis were common among the participants in this research. Food allergy should be considered and tested for in all patients exhibiting symptoms. Given the limitations of currently available diagnostic laboratory tests, the use of an elimination diet followed by food challenge should be considered in cases where laboratory tests do not yield definitive results.

The findings from Study 2 indicate that adults with food allergies may be at risk of experiencing chronic elevated stress and negative mood. Both stress and negative mood have been linked to an increased circulation of stress hormones (Smyth, Ockenfels et al. 1998, van Eck, Berkhof et al. 1996), which in turn has been linked to an increased risk for infections, and the development of insulin resistance disorders, cardiovascular disease, and mental health problems (Cacioppo, Berntson et al. 1998, Cohen, Janicki-Deverts et al. 2007). Therefore, if their stress is not effectively managed (e.g., by access to stress reducing interventions) or prevented (e.g., by addressing the food allergy issues causing the stress), long-term health complications are a real possibility for adults with food allergies. This, along with the risk of stress exacerbating their allergic reactions (Dave, Xiang et al. 2011, Wright, Cohen et al. 2005), indicates that food allergy management may have both short- and long-term implications for the well-being of adults with food allergies. Interventions targeting the top issues identified from this research are likely to reduce stress and improve quality of life for adults with food allergies. Knowledge of which personality traits buffer or, conversely, exacerbate reactivity to the experience of allergy issues can be used to inform the development of interventions that improve ability to cope among individuals with food allergies.

5.3.6 Policy

Problems finding suitable foods to purchase when grocery shopping was one of the top ten issues identified from Study 2 and the results of Study 1 showed that ‘may

contain' labelling was a major contributor to this issue. In addition, 'may contain' labelling contributed to risk-taking, resulting in an increased likelihood of regular physical symptoms and a potential increased burden on the health system. Food labelling policy should address this by implementing mandatory use of a risk assessment tool to determine the use of precautionary labels. This will ensure the food industry takes responsibility and ensure good manufacturing practices are followed to reduce the risk of cross-contamination of allergens into other food products.

In New Zealand, the government needs to work in collaboration with advocacy groups to improve the knowledge and understanding of food allergies among the general public, medical professionals, and within the food service and food industries. Food service- and food industry-related policy should mandate the inclusion of food allergen training as part of education programs for new workers. Provisions should be made for the re-training of individuals already employed in these industries. Educational programs targeting public awareness could include television and radio advertising with personalised stories (e.g., like the campaign to improve understanding of mental health issues).

Government funding of epipens will alleviate anxiety and stress, as well as reducing the financial burden discussed by participants with anaphylaxis. Wider availability of disability allowances for individuals with food allergies, along with provision of information about the existence of this option will reduce the burden (e.g., limitations on food choice, loss of time, and social limitations) associated with the cost of allergen-free food products. Inequality between individuals in rural areas compared with individuals living in cities should be addressed. Government-funded training of rural and small town general practitioners to deal with recognition, diagnosis, and follow-up advice would help to address this inequality.

5.3.7 Food industry

Food service providers and the food industry need to ensure that all members of staff are adequately trained to understand what food allergens are, how food allergies affect individuals, and how to prevent cross-contamination. In addition, food manufacturers should employ a risk assessment tool to determine the use of 'may contain' labels. Based on the current research there appears to be a gap in the market for

inexpensive nutritious allergen-free food products that are appealing in terms of taste and texture. Manufacturers who are able to fill this gap have an improved chance of product success.

5.3.8 *Advocacy*

Based on the findings from Study 1, it is apparent that peer support groups are an important tool to help adults with food allergies adjust to the required dietary and lifestyle changes and cope with ongoing allergy-management-related issues. Advocacy groups need to consider the needs of adults with food allergies separately from the needs of children and the parents of children with food allergies. A campaign to improve the knowledge and understanding of food allergies among the general public would be beneficial to reduce the social impact of food allergies. The current findings support the need for advocacy groups to continue lobbying the government to subsidize the cost of epipens.

5.4 **Limitations**

The individual limitations of Study 1 and Study 2 have been discussed in detail in Chapters 3 and 4, respectively. Further limitations worth noting, in the context of the entire project, are discussed in this section. As indicated in the findings of Study 1, adults with food allergies experience difficulties accessing specialists or general practitioners who are experienced in recognizing and testing for food allergies, therefore there are a limited number of doctor-diagnosed adults with food allergies in New Zealand. For this reason, it was difficult to recruit more participants for this research. A higher number of participants would have added to the generalizability of the findings from Study 2, while a wider range of participants would have benefited both studies. In particular, male participants and participants of Māori and Pacific Island ethnicities proved difficult to recruit. A higher number of male participants would have added value to this research as this would have allowed for better gender comparisons. However, published research has shown that when compared with women, men are less likely to seek healthcare for symptoms, thus reducing the number of available doctor-diagnosed men (Galdas, Cheater et al. 2005). In addition, men are less likely than women to participate in research (Patel, Doku et al. 2003). Recruitment of more Māori and Pacific Island participants may have

added a unique perspective on the lived experiences shared in focus groups (Study 1) and would have allowed for a comparison between some of the major ethnic groups of New Zealand (Study 1 and Study 2). Conversely, due to the cultural differences between these groups and New Zealanders of European descent, the needs of Māori and Pacific Islanders with food allergies may be better addressed by standalone research that is specifically designed to assess their potentially unique perspectives. Finally, the current research provides evidence of an association between allergy issues and daily stress and negative mood. However, this association is correlational and does not prove a causal relationship.

5.5 Conclusions

Food allergy is a growing health concern with implications for consumer vulnerability and health-related quality of life. The current findings show that the needs of adults with food allergies living in New Zealand are not being adequately met. The frequency at which adults with food allergies experience issues in daily life has implications for their day-to-day psychological functioning and places them at risk of stress-related health complications (e.g., frequent infections, insulin resistance disorders, cardiovascular disease, and mental health problems). In addition, the stress associated with allergen avoidance may cause more severe symptoms at times when the allergen is accidentally ingested. Behavioural changes to avoid stressful situations may lead to social isolation and poorer daily functioning. The psychological, social, and physical functioning of adults with food allergies can be improved using interventions targeting the prevention of food allergy issues and/or access to training in stress management techniques (e.g., cognitive-behavioural stress management). Interventions targeting prevention of food allergy issues should address the top issues identified in this research.

5.6 Future research

It would be interesting to collect more data from male participants to allow a detailed male-female comparison (i.e., check if men and women experience life with food allergies differently). In addition, a cross-cultural comparison between the main ethnic groups of New Zealand would be valuable. Māori and Pacific Islanders have a high

prevalence of asthma and eczema symptoms (Ellison-Loschmann, Pattemore et al. 2009, Clayton, Asher et al. 2013). Therefore, they may also have a high prevalence of food allergies as food allergies, eczema, and asthma commonly occur together (Skypala and Venter 2009, Liu, Jaramillo et al. 2010). Cultural differences may influence how these ethnic groups experience food allergies and the types of issues they face. It would therefore be interesting to look at the experience of food allergies in these populations.

Other areas of research that would extend on the knowledge gained from this thesis include comparing doctor-diagnosed participants with those who have self-diagnosed food allergies, comparing populations of food allergic adults from different countries, and repeating the study with a sample of New Zealand children with food allergies and their parents. A study comparing the results of the daily measure developed in this research with the results of a validated food allergy-specific health-related quality of life measure in the same population would add to knowledge about how food allergy experiences are remembered across time.

The results presented in this thesis highlight the importance of a quick and accurate diagnosis in enhancing the quality of life of individuals with food allergies. Further research is needed to improve diagnostic techniques for food allergies, particularly in the case of non-IgE-mediated food allergies other than coeliac disease. Finally, there is a need for better prevalence data to allow policymakers to understand the proportion of the population affected by food allergies. A combination of accurate prevalence data presented in conjunction with the findings presented in this thesis would make a compelling case to policymakers to effect change.

5.7 Concluding statement

This thesis has identified the issues that impact on the quality of life of New Zealand adults with food allergies and quantified their frequency and level of impact in daily life. In addition, this thesis has shown that socio-demographic factors (rural vs urban living, gender, income, and age), food allergy factors (time since diagnosis and number of food allergies), and personality traits can influence food allergy related experiences (e.g. frequency and/or type of issues, and impact of issues on quality of life). Strategies to improve the quality of life of adults with food allergies could involve clinicians (e.g., interventions targeting stress reduction), the government (e.g. policy

changes for ‘may contain’ labelling, funding for improved specialist healthcare provision), the food industry (e.g., food allergen training for staff, development of low-cost nutritious and tasty allergen-free products), and advocacy groups (e.g. support groups, public education).

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APPENDICES

Appendix A: Focus group facilitator’s guide.....	154
Appendix B: Ethics approval.....	156
Appendix C: Participant information sheets and consent forms	157
Appendix D: Copy of daily survey.....	161
Appendix E: Hierarchical linear modelling	166
Appendix F: Table A-1. Full list of daily allergy issues, proportion of participants affected, frequency of reporting, and their average perceived stress/impact scores. Issues are listed from the highest to the lowest proportion of participants affected.	169

Appendix A: Focus group facilitator's guide

Welcome: (5-10 minutes)

Provide refreshments (tea, coffee, juice, water, biscuits/nibbles) and ask for consent forms to be completed. Get the group seated.

Icebreaking exercise: (10 minutes)

1. Outline the aims of the focus group.

Aims: The overall aim of this research is to better understand the issues affecting the lives of NZ adults with food allergies. The aims of the focus groups are to identify the issues that affect the lives of NZ adults with food allergies, and to understand how they feel about these issues, how their lives are affected, and what strategies might be useful to make their food allergies easier to live with.

2. Definition of food allergy (WHO)
3. Explain my role at the focus group:

“I would like to get an open discussion going about your experiences of living with a food allergy. This discussion will be based around a few core topic areas (healthcare system/ symptoms, food supply/nutrition, cost – financial & time, social, and psychological) but will also leave room for other issues that may not necessarily fall into any of these general topic areas. The time available will allow for about 15 minutes of discussion per topic area, although we may find some topic areas require slightly more time and others slightly less. This should allow for a spare 15 minutes to discuss any issues that fall outside of the main topic areas. My role in the discussion will be as a facilitator of the discussion (e.g., to keep the discussion going, and to keep it focused), rather than an active participant. I would like to see interaction and discussion within the group about the issues brought up by individuals, which will allow me to learn more about similarities and differences within the group with respect to: which issues affect you, how you are affected by the different issues, and what you think could be done to make your life with food allergies easier.”

4. Ask participants to say their first name, state what food/s they are allergic to & tell the group briefly about their food allergy story (1 min). Then ask participants to briefly

tell the group about one positive experience they've had in relation to their food allergy.

Introductory exercise: (5-10 minutes)

1. Tell participants: "Just to get you started thinking about the different issues that affect your lives, I have short introductory exercise for you to complete."
2. Give each participant a sheet with 10 statements relating to food allergy. Ask participants to rate each of the statements in terms of their importance or impact on their personal experience of having a food allergy. Exercise should take about 2 minutes & ask participants to hand sheets back to me when finished.

Rating of 0 = not at all important/no impact, 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 are based on what was listed as top 3 issues in recruitment surveys)

Group discussion: (up to 90 minutes)

Topic guide: show categories on whiteboard – healthcare system & symptoms, food supply/nutrition, cost, social, psychological. Main question: What issues influence or have influenced your experience of living with a food allergy?

Additional questions to use if necessary to keep conversation flowing:

1. For each identified factor, ask (if necessary):
 - a. In what way/s does this influence your life?
 - b. How does that make you feel about your food allergy?
 - c. How does it make you feel about yourself, as a person with a food allergy?
 - d. What could be done to make this factor/issue less of a problem for you?
2. Which issues are a particular problem early on after diagnosis and which issues continue to cause problems on an ongoing basis?
3. Which of these issues impact on your life negatively on a regular basis? (daily/weekly/monthly)?

Appendix B: Ethics approval

DEPARTMENT OF PSYCHOLOGY ETHICAL APPROVAL OF A CATEGORY B PROJECT INVOLVING HUMAN PARTICIPANTS

Title: *The Impact of Living with Food Allergies on Quality of Life*

Projected Dates: July 2011 – Dec 2013

Participants: Population: Community Adults
Age range: >18 years old

Number: 50 for focus groups; 100 – 200 for daily assessment

How recruited: PSYC 100 Internal Assessment Option

Other – through recruitment flyer (attached)

Details of Nature of Task/Procedure: (Attach copies of information sheet, consent form, and questionnaires, if applicable.)

-See enclosed description-

****Please note this protocol is also under review with the Department of Food Science. We are seeking ethical approval through both departments as this project is a collaboration between both departments.

No information that could be used to identify an individual participant will be collected in this experiment. [NB: Basic demographic information will be collected and identified by ID only; the link between name and ID will be password protected and destroyed upon completion of the study.]

ETHICAL ISSUES:

Is deception involved?

YES/NO

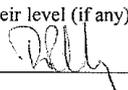
Could there be any possible harm or discomfort to participants? (If YES, explain)

YES/NO

Details of any other ethical issues involved (eg, payment, community relations, controversial topic, etc):

Name of Staff Member: Tamlin Conner (w/ Miranda Miroso – Food Science) Signature:  Date: 23/5/11

Names of Participating Students and their level (if any): Rana Peniamina

Approval by Head of Department:  Date: 7/6/11 Approval No: DP 18/11

Copy sent by HOD to OU Human Ethics Committee:

Available on "S" Drive, "Office" "Forms" "HumanEthics"

Appendix C: Participant information sheets and consent forms

Reference Number DP18/11
14 July 2011



THE IMPACT OF LIVING WITH FOOD ALLERGIES ON QUALITY OF LIFE: FOCUS GROUPS INFORMATION SHEET FOR PARTICIPANTS

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the Aim of the Project?

To better understand the issues affecting the lives of adults with food allergies. This will include looking at how adults with food allergies feel about these issues, how these issues affect their lives, and what could be done to make their lives with food allergies better. The research will also examine whether there are any groups of people (based on classifications such as age, gender, ethnicity, type of food allergy, etc) who are affected more by certain food allergy-related issues compared to other groups. If any group is identified as being affected more, specific help can be recommended for that group of people.

This project is being undertaken as part of the requirements for a PhD degree.

What Type of Participants are being Sought?

We are looking for participants who have a food allergy that has been professionally diagnosed by their GP doctor or by an allergy specialist doctor. Participants should be at least 18 years of age. We would like to recruit a large group of participants of a wide range of backgrounds that is representative of the New Zealand adult population. Ideally the group of participants recruited will include people with different types and severity of food allergies.

What will Participants be Asked to Do?

Should you agree to take part in this project, you will be asked to attend a focus group session to discuss your experiences of living with a food allergy. The focus group will consist of 6-12 people with food allergies and is expected to last about 1-2 hours. Upon completion of the focus group session you will be given a \$20 petrol voucher to compensate you for your time and travel costs to the focus group venue.

You may also be asked if you are willing to be contacted for further questions if such questions arise after the focus group information has been processed. In addition, you may be invited to take part in a follow up study of your day-to-day experiences at a later date (with no obligation to participate). Please be aware that you may decide not to take part in the project without any disadvantage to yourself of any kind.

What Data or Information will be Collected and What Use will be Made of it?

General personal information about yourself and your food allergy will be collected by way of a short questionnaire during the recruitment phase prior to the focus group session. This will

be used for statistical purposes only and will not be made available to anyone in any format that will link you to the information. Only the researcher will have access to the information in its unprocessed state.

The focus group session will be video-recorded to allow the researcher to remember and accurately transcribe what was said during the session. The video recording and transcript will not be shared with anyone outside the current research. Moreover, you may request a copy of the focus group transcript and withdraw parts of it, if desired. The information collected from the focus group session will be used to summarize the issues that people with food allergies face in their daily lives, and the relative importance of the different issues.

The data collected will be securely stored in such a way that only those mentioned below will be able to gain access to it. At the end of the project any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the project depend will be retained in secure storage for five years, after which it will be destroyed. The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve your anonymity. If participants would like to be provided with a copy of the results of this study they can request this by ticking the option for this at the bottom of the consent form.

The focus group involves an open-questioning technique in a group of 6-12 people. The general line of questioning will involve a discussion of your personal experiences of living with a food allergy (i.e. the ways in which having a food allergy impacts on your life) and what approaches could be useful in reducing the impact of your food allergy on your life and thus improving your quality of life. The precise nature of the questions which will be asked has not been determined in advance, but will depend on the way in which the focus group discussion develops. Consequently, although the Human Ethics Committees of the Department of Food Science & Department of Psychology are aware of the general areas to be explored in the interview, the Committees have not been able to review the precise questions to be used. In the event that the line of questioning does develop in such a way that you feel hesitant or uncomfortable you are reminded of your right to decline to answer any particular question(s) and also that you may withdraw from the project at any stage without any disadvantage to yourself of any kind.

This proposal has been reviewed and approved by the Department of Food Science and the Department of Psychology, University of Otago.

Can Participants Change their Mind and Withdraw from the Project?

You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind.

What if Participants have any Questions?

If you have any questions about our project, either now or in the future, please feel free to contact either:

Rana Peniamina
Department of Food Science
University Telephone Number:
03-4799198

or

Dr Miranda Miroso
Department of Food Science
University Telephone Number:
03-4797953

This study has been approved by the Departments stated above. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479-8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.



**THE IMPACT OF LIVING WITH FOOD ALLERGIES ON QUALITY OF LIFE:
FOCUS GROUPS**

CONSENT FORM FOR PARTICIPANTS

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:-

1. My participation in the project is entirely voluntary;
2. I am free to withdraw from the project at any time without any disadvantage;
3. Personal identifying information, including video recordings of the focus group sessions, will be destroyed at the conclusion of the project but any raw data on which the results of the project depend will be retained in secure storage for at least five years;
4. This project involves an open-questioning technique where the precise nature of the questions which will be asked have not been determined in advance, but will depend on the way in which the focus group session develops and that in the event that the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s) and/or may withdraw from the project without any disadvantage of any kind;
5. On completion of the focus group session, I will be compensated for my time and travel expenses by way of a \$20 petrol voucher;
6. I may request a copy of my transcript and withdraw parts of it, if desired. I am also entitled to request a copy of the published project;
7. The results of the project may be published and available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve my anonymity.

I agree to take part in this project.

.....
(Signature of participant)

.....
(Date)

Please send me a copy of the published project once it is available.

Email address to send copy of published project to:

THE IMPACT OF LIVING WITH FOOD ALLERGIES (DAILY QUESTIONNAIRES): INFORMATION SHEET FOR PARTICIPANTS



Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you of any kind and we thank you for considering our request.

What is the aim of the project?

To better understand what issues cause problems for people with food allergies in their daily lives, and the relative importance of the different issues. The research will also examine whether there are any groups of people (based on classifications such as age, gender, ethnicity, type of food allergy, etc) who are affected more by certain food allergy-related issues compared to other groups. If any group is identified as being affected more, specific help can be recommended for that group of people.

This project is being undertaken as part of the requirements for a PhD degree.

What type of participants are being sought?

We are looking for participants who have a food allergy that has been professionally diagnosed by their GP doctor or by a specialist doctor. Participants should be at least 18 years of age, and have nightly access to the internet. We would like to recruit a large group of participants (more than 100) of a wide range of backgrounds that is representative of the New Zealand adult population. Ideally the group of participants recruited will include people with different types and severity of food allergies.

What will participants be asked to do?

Should you agree to take part in this project, you will be asked to complete an initial online survey collecting socio-demographic, personality, and food allergy information. This survey will take 20-30 minutes to complete. You will then be asked to complete a short online questionnaire each day (will take about 5 minutes to complete) for a period of two weeks. In it, you will be asked about what impact (if any) different issues related to your food allergy had on your life that particular day. You will receive a text reminder (to the mobile phone number you provide upon registration) at 8pm every evening on the days a survey should be completed.

What data or information will be collected and what use will be made of it?

General personal information about yourself and your food allergy will be collected in the initial questionnaire. This will be used for statistical purposes only and will not be made available to anyone in any format that will link you to the information. Only the researcher will have access to this information in its unprocessed state.

The questionnaire data will be collected over a secured server and stored in such a way that only those mentioned below will be able to gain access to it. Your data will be identified by an ID number only, not your name. At the end of the project any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the project depend will be retained in secure storage for five years, after which it will be destroyed.

The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve your anonymity. If participants would like to be provided with a copy of the results of this study they can request this by ticking the option for this at the bottom of the consent form.

Can participants change their mind and withdraw from the project?

You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind.

What if participants have any questions?

If you have any questions about our project, either now or in the future, please feel free to email us via the study email address (foodallergystudynz@gmail.com) or contact either:

Rana Peniamina
Department of Food Science
University Telephone Number:
03-4794778

or

Dr Miranda Miroso
Department of Food Science
University Telephone Number:
03-4797953

This study has been reviewed and approved by the Department of Food Science and the Department of Psychology, University of Otago. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479-8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

INFORMED CONSENT

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I will be entered into a prize draw (as outlined on the study website) as thanks for my participation. I understand that I am free to request further information at any stage.

- I agree to take part in this project.
 I would like to receive a personalised report of the study results.

REGISTRATION

Email address:

Repeat email address:

Password to access study questionnaires:

Repeat password:

Mobile telephone number:

Repeat mobile telephone number:

SUBMIT & GO TO THE INITIAL SURVEY NOW (survey will take about 20-30 minutes)

SUBMIT (ACCESS INITIAL SURVEY AT A LATER DATE) Note: you will need to complete the initial survey within 1 week of registering.

Section 2.

The following questions will relate specifically to problems or issues you may have experienced TODAY as a result of your food allergy.

5. Have any food allergy related issues affected you today? (see list below as a guide)
- YES NO

If participants selected NO, they were taken directly to section 4.

If participants selected YES they were presented with the following question:

6. Please select which food allergy related issues affected you today (select all options that apply):

Allergen free eating

- Problems with finding suitable foods to eat when away from home (e.g., no safe foods, no healthy options).
- Problems with finding suitable foods to purchase when grocery shopping.
- Having to take risks by eating foods that may contain allergens.
- Having to go hungry/not eat because there is no safe food available.
- Problems finding a restaurant or café that can provide an allergen free meal.
- Missing out on foods because of the cost of allergen free products.
- Trouble with maintaining a healthy, nutritionally balanced diet as a result of my food allergy.

Financial cost

- Extra financial cost due to higher food prices for safe foods.
- Extra financial cost due to medical expenses resulting from the food allergy (e.g., doctor's visits regarding food allergy, treatment for food allergy symptoms).

Time cost

- Loss of time due to extra time spent sourcing safe food (e.g., reading labels, going to different shops).
- Loss of time due to extra time spent preparing meals.
- Loss of time due to extra time spent organizing food (e.g., packing safe food to bring along when out, pre-preparing meals to store in freezer).

Personal cost

- Avoiding participation in social occasions because of food allergy.
- Being excluded from social occasions because of food allergy.
- Feeling anxious or stressed when participating in social occasions involving food.
- Difficulties travelling with food allergies.

External influences

- Lack of understanding from others in relation to my food allergy. Select the situation/s in which this was experienced today:
 - At the doctor
 - Dealing with other medical professionals
 - At a restaurant/café (involving restaurant/café staff)
 - At a social gathering (dealing with peers)
 - At a family gathering (dealing with family members)
 - At work
 - Other, please describe briefly:

- People being uncooperative or unkind towards me because of my food allergy. Select the situation in which this was experienced today:
 - At the doctor
 - Dealing with other medical professionals
 - At a restaurant/café (involving restaurant/café staff)
 - At a social gathering (dealing with peers)
 - At a family gathering (dealing with family members)
 - At work
 - Other, please describe briefly:

Physical effects

- Physical symptoms of food allergy. What type of symptoms did you experience today? (Please select all options that apply)
 - Cardiovascular symptoms (e.g., lightheadedness, dizziness, palpitations, loss of vision, collapse, loss of consciousness)
 - Respiratory (e.g., shortness of breath, difficulty breathing, wheezing)
 - Gastrointestinal (e.g., nausea, abdominal cramps, vomiting, diarrhoea)
 - Skin (e.g., itchy skin, red rash, eczema, hives, swelling of the skin)
 - Nose/eyes (e.g., itchy eyes, watery eyes, nasal congestion, sneezing)
 - Oral (swelling or itchiness of mouth/tongue/throat)
 - Other, please list:

Psychological issues

- Feeling anxious about whether food is safe to eat.
- Feeling anxious about potentially having an allergic reaction.
- Feeling embarrassed as a result of my food allergy.
- Feeling inadequate or defective as a result of my food allergy.
- Feeling anxious about how people will react if I reveal my food allergy.

Other issues

- Other, please describe briefly:

Section 3.

Now, think about how much impact the issues you selected had on your life today.

If participants selected more than three issues, they were presented with question 7.

Participants who selected three or fewer issues skipped question 7.

7. Please select the three (3) issues that had the most impact today.

Participants were presented with a list of the issues they selected in Section 2 so they could select the three issues that had the most impact.

8. Issue 1: (*Name of first issue selected*)

How stressful was this issue for you?

Not very stressful *Moderately stressful* *Very stressful*

How much impact did this issue have on your ability to actively participate in normal daily tasks? (e.g., work, household activities, social commitments, family commitments)

Very little impact *Moderate impact* *High impact*

Issue 2: (*Name of second issue selected*)

How stressful was this issue for you?

Not very stressful *Moderately stressful* *Very stressful*

How much impact did this issue have on your ability to actively participate in normal daily tasks? (e.g., work, household activities, social commitments, family commitments)

Very little impact *Moderate impact* *High impact*

Issue 3: (*Name of third issue selected*)

How stressful was this issue for you?

Not very stressful *Moderately stressful* *Very stressful*

How much impact did this issue have on your ability to actively participate in normal daily tasks? (e.g., work, household activities, social commitments, family commitments)

Very little impact *Moderate impact* *High impact*

Section 4.

9. Is there anything else you would like to share about your experiences of having a food allergy today?

YES, please describe briefly:

NO

THANK YOU FOR COMPLETING TODAY'S SURVEY.

Appendix E: Hierarchical linear modelling

Main analyses

Multilevel models were run to examine the within-person associations between food allergy issues experienced and the outcomes (stress, negative mood, positive mood, and physical energy). This approach took into account the nested nature of the data with reports of food allergy issues experienced, daily stress, negative mood, positive mood, and physical energy (at level-1) nested within individuals (at level-2). Multilevel regression models were run in HLM 7 (Raudenbush, Bryk et al. 2011) for each outcome separately (stress, negative mood, positive mood, and physical energy). In each model, the outcome (e.g., daily stress: DSTRESS) was predicted by the number of food allergy issues experienced (ISSPDAY). The level-1 and level-2 equations were as follows:

Level-1 Model

$$\text{DSTRESS} = B_0 + B_1 * (\text{ISSPDAY}) + r$$

Level-2 Model

$$B_0 = G_{00} + U_0$$

$$B_1 = G_{10} + U_1$$

where DSTRESS was the outcome; B_0 was each individual's stress at their mean number of issues per day; and B_1 was each individual's change in stress when number of issues increased above the mean. ISSPDAY was group-mean centred. There were no predictors at level-2 in this equation. G_{00} was the mean stress at mean number of issues; and, G_{10} was the mean change in stress when issues increased above the mean. A significant G_{10} coefficient indicated that individuals experienced changes in stress (or mood, energy) on days with more (vs fewer) food allergy issues.

Supplementary analyses

This set of analyses was run to examine whether demographic factors (age, gender, income level, symptom severity, number of food allergies, and type of food allergy) and personality traits (neuroticism, openness, extraversion, agreeableness, and conscientiousness) moderated the level-1 relationships between food allergy issues per day and the outcomes (stress, negative mood, positive mood, and physical energy). The

level-1 models were the same as in the main analyses; the level-2 models included a series of predictors that were entered and tested separately (age, gender, income level, symptom severity, number of food allergies, and type of food allergy). An example equation with age as the level-2 moderator is shown below:

Level-1 Model

$$\text{DSTRESS} = B_0 + B_1 * (\text{ISSPDAY}) + r$$

Level-2 Model

$$B_0 = G_{00} + G_{01} * (\text{AGE}) + U_0$$

$$B_1 = G_{10} + G_{11} * (\text{AGE}) + U_1$$

Age was centred around the grand mean. G_{00} was the mean daily stress at mean number of issues for participants at the mean age (age 40); G_{01} indicated whether mean daily stress at the mean number of issues varied as a function of age; G_{10} was the change in stress when issues increased above the mean for participants at the mean age (age 40); and G_{11} was the within-person relationship between daily stress and number of issues varied as a function of age. A significant G_{11} coefficient indicated significant moderation. In subsequent models, the AGE variable was recentred at -1, + 1, + 2 standard deviations, and the G_{10} coefficients examined to determine the significance of the within-person relationships for participants of different ages. A similar procedure was followed for the income level, and personality traits which were also continuous predictors and centred around the grand mean.

Gender was entered as an uncentred level-2 predictor (0 = male; 1 = female). G_{00} was the mean daily stress at mean number of issues for male participants; G_{01} indicated whether mean daily stress at the mean number of issues differed for female participants; G_{10} was the change in stress when issues increased above the mean for male participants; and G_{11} indicated whether the within-person relationship between daily stress and number of issues differed for female participants. Again, a significant G_{11} coefficient indicated significant moderation by gender. A similar procedure was followed for allergy severity, which was also a categorical and uncentred predictor (0 = participants without anaphylaxis, 1 = participants with anaphylaxis).

Number of food allergies was first grouped into three categories (1, 2, 3+ allergies) and dummy coded (dummy 1: 1 allergy = 1, all others = 0; dummy 2: 2 allergies = 1, all others = 0; dummy 3: 3+ allergies = 1, all others = 0). The level-2 intercept was dropped from the equation:

Level-1 Model

$$\text{DSTRESS} = B_0 + B_1 * (\text{ISSPDAY}) + r$$

Level-2 Model

$$B_0 = G_{01} * (\text{Dummy 1}) + G_{02} * (\text{Dummy 2}) + G_{03} * (\text{Dummy 3}) + U_0$$

$$B_1 = G_{11} * (\text{Dummy 1}) + G_{12} * (\text{Dummy 2}) + G_{13} * (\text{Dummy 3}) + U_1$$

where $G_{11} - G_{13}$ indicated the within-person relationship between allergy issues and stress (or mood or physical energy) for each group (those with 1, 2, or 3+ allergies, respectively). The multivariate hypothesis testing option was then used to compare differences between coefficients ($G_{11} - G_{13}$).

Similarly, type of food allergy was grouped into five categories and dummy coded (dummy 1: gluten/wheat allergy = 1, no gluten/wheat allergy = 0; dummy 2: peanut/treenut allergy = 1, no peanut/treenut allergy = 0; dummy 3: shellfish/seafood allergy = 1, no shellfish/seafood allergy = 0; dummy 4: Cow's milk allergy = 1, no cow's milk allergy = 0; dummy 5: Other allergy = 1, no other allergy = 0). Following the same modelling as above, the level-2 intercept was dropped from the equation and the multivariate hypothesis testing option was used to compare differences between coefficients ($G_{11} - G_{15}$).

References

Raudenbush, S. W., Bryk, A. S., & Congdon, R. (2011). HLM 7 for Windows (Computer software, student version). Skokie, IL: Scientific Software International, Inc.

Appendix F: Table A-1. Full list of daily allergy issues, proportion of participants affected, frequency of reporting, and their average perceived stress/impact scores. Issues are listed from the highest to the lowest proportion of participants affected.

Issue	Proportion of participants (%) ^a	Frequency (%) ^b	Perceived stress	Perceived impact
Problems finding suitable foods to eat when away from home	65.7	15.3	2.5	2.1
Extra financial cost due to higher food prices for safe food	63.0	17.0	3.0	2.3
Having to take risks by eating foods that may contain allergens	57.4	13.4	2.6	2.1
Loss of time due to extra time spent sourcing safe food	52.8	12.4	2.2	2.1
Physical symptoms of food allergy	49.1	17.4	2.9	2.7
Feeling anxious about whether food is safe to eat	48.1	11.8	2.9	2.3
Having to go hungry/not eat because there is no safe food available	46.3	9.7	2.7	2.6
Feeling anxious or stressed when participating in social occasions involving food	41.7	7.9	2.9	2.3
Problems with finding suitable foods to purchase when grocery shopping	39.8	5.7	2.9	2.3
Loss of time due to extra time spent preparing meals	38.9	9.8	2.2	2.5
Feeling embarrassed as a result of my food allergy	38.0	7.4	2.8	2.0
Avoiding participation in social occasions because of food allergy	37.0	5.8	2.3	2.4
Feeling anxious about potentially having an allergic reaction	37.0	8.0	2.7	2.1

Table A-1. Full list of daily allergy issues, proportion of participants affected, frequency of reporting, and their average perceived stress/impact scores, continued

Issue	Proportion of participants (%) ^a	Frequency (%) ^b	Perceived stress	Perceived impact
Loss of time due to extra time spent organizing food	37.0	8.6	1.8	2.1
Problems finding a restaurant or café that can provide an allergen free meal	36.1	4.3	2.6	2.3
Lack of understanding from others in relation to my food allergy	35.2	8.0	3.1	2.6
Trouble with maintaining a healthy, nutritionally balanced diet as a result of my food allergy	35.2	11.6	2.9	2.4
Feeling inadequate or defective as a result of my food allergy	24.1	4.9	3.1	2.7
Being excluded from social occasions because of food allergy	22.2	2.9	2.6	2.9
Difficulties travelling with food allergies	21.3	3.7	2.9	2.7
Missing out on foods because of the cost of allergen free products	20.4	5.1	3.3	2.8
Feeling anxious about how people will react if I reveal my food allergy	18.5	2.9	2.6	1.9
Extra financial cost due to medical expenses resulting from the food allergy	15.7	2.7	2.7	2.2
People being uncooperative or unkind towards me because of my food allergy	7.4	1.1	3.5	3.5
Other issues	33.3	5.6	2.3	2.0

^aProportion of participants = percentage of participants who selected the issue at least once. ^bFrequency % = percentage of reports in which issue was selected (reports issue selected/total reports x 100).