

“They Thought I was Just Joking About It”:
Experiences and Perceptions of Food Allergy
in New Canadians from Asia

by
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AUTHOR'S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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ABSTRACT

Perceived increased prevalence and levels of awareness of food allergy has become a global phenomenon, making it a major public health concern. Although little is known about its etiology or prevalence, substantial variation in prevalence on a global scale is evident. Studies on food allergy in Asia are reporting an increase in prevalence, particularly in economically developed regions like Hong Kong. Interestingly, risk perception studies have found that Canadians' perceived prevalence of food allergy surpasses systematic estimates. Moreover, Canadian immigrants are more likely to rate the risk of food allergy as "high" compared to non-immigrants. To explore these issues further, qualitative interviews were conducted with key informants (n=3) and allergic individuals of Asian descent (n=18) in order to capture their lived experience with food allergies. Interviews lasted 30 minutes on average and they were tape recorded and transcribed verbatim for subsequent thematic analysis using QSR International's NVivo 9. Results are organized around four major themes: perceived prevalence, risk perception, management and coping, and quality of life. With respect to perceived prevalence and risk, participants found food allergies to be more common in Canada than in Asia. Participants also agreed that having a food allergy is more manageable in Canada as a result of the policy environment (e.g., food labelling and school board policies). In addition, participants had dealt with skepticism and disbelief about their food allergy in Asia, impacting their quality of life. These findings demonstrate the need to recognize the varied impacts and experiences of food allergy among new Canadians, given that immigrants represent a large and growing proportion of the Canadian population.

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CHAPTER ONE

Introduction

According to the National Institute of Allergy and Infectious Diseases (NIAID), a *food allergy* is “an adverse health effect arising from a specific immune response that occurs reproducibly upon exposure to a given food” (Chaudhry & Oppenheimer, 2012). This specific immune response refers to the reaction that is a result of the interaction of IgE antibodies with food protein (Gelinick et al., 2008). In its most severe form, an IgE-mediated food allergy can lead to *anaphylaxis*, which is defined as two or more of the following characteristics after exposure: a) involvement of skin or mucosa, b) respiratory compromise, c) cardiovascular compromise, and/or d) persistent gastrointestinal symptoms (Ben-Shoshan & Clarke, 2011).

There is currently no curative treatment for food allergies. Food immunotherapy has been tried, but it is only in its infancy (Otsu & Fleischer, 2012). Fortunately, there is medication available that can delay the onset of symptoms of an anaphylactic reaction (Anaphylaxis Canada, 2011). Self-administered epinephrine is the most commonly used medication and it can save a life provided that it is administered immediately and emergency care is timely (Anaphylaxis Canada, 2011). However, the risk of anaphylaxis remains high. Dietary exclusion is the only way for allergic individuals to avoid accidental exposure to food allergens. Responsible management of a food allergy also involves reading food labels, taking extra precautions in food preparation, and being diligent in hand washing (Anaphylaxis Canada, 2011). Moreover, risk of accidental exposure is exacerbated by inconsistent and inappropriate food labelling and cross-contamination (Chow, 2011; Sheth et al., 2010; Vierk et al., 2007). The wide variety of international foods that have changed eating habits and become a regular part of many people’s diet complicates the task of reading ingredient lists and labels (Sora et al., 2009). Thus, the extra responsibilities and

dietary restrictions that are demanded of allergic individuals can have a significant impact on their quality of life. Studies suggest that families with young children at risk of anaphylaxis, in particular, experience a detrimental effect on quality of life because of their condition (Chow, 2011; Fenton et al., 2011; Gupta et al., 2008).

1.1 Research Context

On an international scale, food allergy prevalence varies widely with age and geographic location. Prevalence has been reported to affect anywhere between 2-10% of a population (Sicherer, 2011). In Canada, the first estimates of prevalence were published in 2010. It was reported that 7.14% of children and 6.56% of adults have a food allergy, making the overall estimated prevalence 6.67% (Soller et al., 2012). The five most common allergens in the Canadian population were identified as peanut, tree nut, sesame, fish, and shellfish (Ben-Shoshan et al., 2012a). Despite these findings, the overall prevalence of food allergy in Canada remains uncertain. The initial estimates were based on a sample population that underrepresented Canadians of lower socioeconomic status and immigrants (Ben-Shoshan et al., 2012a). Although the estimates of prevalence in Canada were relatively consistent with other countries of similar economic standing, it is possible that prevalence was overestimated due to reliance on self-report and possible bias from non-response (Soller et al., 2012; Vierk et al., 2007).

Another uncertainty is whether or not the prevalence of food allergies has increased over the last two decades, as is the common perception of the general public (Rona et al., 2007). This perception coincides with the increased presence of stories related to food allergies in the Canadian media (Harrington et al., 2012a). Increased interest in food allergies also reflects the many uncertainties that surround its etiology and occurring changes in prevalence.

Perceived prevalence of food allergies in Canada, on the other hand, can be confirmed. A study by Harrington et al. (2012a) found that the perceived prevalence of food allergy surpasses systematic estimates by up to 30%. The gap between perceived and technical risk of food allergy suggests that the public understanding of food allergy is, in fact, inflated (Harrington et al., 2012b). Newly-immigrated Canadians (hereon referred to as new Canadians), in particular, were more likely to rate the risk of food allergy as “high” compared to non-immigrants or immigrants who have lived in Canada for over 10 years (Harrington et al., 2012b). Interestingly, a food allergy was less likely to be reported in a household of new Canadians compared to other households in the study by Ben-Shoshan et al. (2012a).

1.2 Research Objectives

An explanation for the findings described above has yet to be found. Moreover, food allergies will remain a public health concern among the Canadian population until the complex interplay between gene and environmental factors is deciphered and a cure is found. For these reasons, the social constructionist approach was used as a means to explore the psychosocial impact of anaphylaxis. Researchers have already sought the perspectives of food-allergic children (Avery et al., 2003; Fenton et al., 2011; Hu et al., 2005), adolescents (Akeson et al., 2007; Sampson et al., 2006), their parents (Akeson et al., 2007; Hu et al., 2005; Mandell et al., 2005), allergists (Xu et al., 2010), and the general public (Gupta et al., 2008; Sora et al., 2009); however, none until now have explored the impact of food allergies on the quality of life of new Canadians. Therefore, the purpose of this thesis is to examine the gap between perceived risk of food allergy and estimates of prevalence in new Canadians. Three objectives guided this research:

- 1) To explore the policy context around food allergy for new Canadians

- 2) To understand how a specific ethnocultural group perceives food allergies and its associated risks
- 3) To appreciate how new Canadians manage and cope with food allergies

The chosen study design and methods of this thesis are based on social constructionism. It is anticipated that a deeper understanding of an individual's lived experiences and perceptions of food allergy allows us to examine the influence of policy on their quality of life. The objectives were met by conducting a documentary analysis of policy and/or resource documents related to food allergy and in-depth interviews with key informants and allergic individuals. These three forms of data collection complement one another and together they add validity to findings.

1.3 Research Contributions

This thesis makes a substantive contribution to the current literature on food allergies and immigrant health. Canadian immigrants, as a population group, are often overlooked in health research because they are generally more difficult to recruit. The underrepresentation of diverse groups in research is problematic because it limits our understanding of the social determinants of health and it undermines our ability to effectively address health inequalities (Lakes et al., 2012; Rooney et al., 2011).

From a theoretical standpoint, this thesis contributes to the growing number of examples that have used the social constructionist approach in a health context. The social constructionist approach has been successful in helping us understand the impact of food allergy on affected individuals, and the intent of this thesis is to do the same. Furthermore, as part of a larger Canadian research program on food allergies, qualitative findings from this thesis and others of similar design will be used to inform the next stage of quantitative data collection that will consist of the third round of a cross-sectional survey on food allergies at the national level.

This thesis also makes methodological contributions to qualitative research by using the triangulation approach as a means to establish rigour. The documentary analysis of policy and/or resource documents and key informant interviews were used to establish the political and social context in which new Canadians are living. These perspectives then helped frame the questions that were asked during in-depth interviews with affected individuals. All three methods of data collection were effective tools to understanding the allergic experience of new Canadians, especially when used in conjunction.

1.4 Chapter Outline

This thesis consists of five chapters. Chapter 2 is a literature review of work pertaining to food allergies and their impact on quality of life. The review also covers previous studies that have used the social constructionist approach to understand health. Chapter 3 discusses study design and methods used to collect qualitative data. Methods for establishing rigour in qualitative research are also covered. The results of this thesis are presented in Chapter 4. Common perceptions and experiences that emerged from in-depth interviews with key informants and participants are described and organized according to theme. Finally, Chapter 5 highlights major findings of this thesis and links them with findings from other published results. Chapter 5 also explains the policy implications of this thesis and provides suggestions for further research.

CHAPTER TWO

Literature Review

2.1 Introduction

Both quantitative and qualitative research methods have contributed to our current understanding of food allergies. Epidemiological studies have focused on prevalence and demographic predictors of food allergy across different age groups on a global scale. Qualitative studies, many of them informed by social theory, have examined the impact of food allergies on quality of life by revealing the lived experiences of affected individuals. This chapter provides a review of both types of literature that have led to our main research question; that is, why do new Canadians perceive the risk of food allergy to be high, if studies suggest that prevalence of food allergy in new Canadians is low? The objectives of this thesis are:

- 1) To explore the policy context around food allergy for new Canadians
- 2) To understand how a specific ethnocultural group perceives food allergies and its associated risks
- 3) To appreciate how new Canadians manage and cope with food allergies

The appropriateness of qualitative methods for addressing these research objectives is also discussed.

2.2 Food Allergy

According to the National Institute of Allergy and Infectious Diseases (NIAID), a food allergy is “an adverse health effect arising from a specific immune response that occurs reproducibly upon exposure to a given food” (Chaudhry & Oppenheimer, 2012). This specific immune response refers to the reaction that is a result of the interaction of IgE antibodies with food protein (Gelinick et al., 2008). In its most severe form, an IgE-mediated food allergy can

lead to anaphylaxis, which is defined as two or more of the following characteristics after exposure: a) involvement of skin or mucosa, b) respiratory compromise, c) cardiovascular compromise, or d) persistent gastrointestinal symptoms (Ben-Shoshan & Clarke, 2011). In contrast, non-allergic food hypersensitivity is not mediated by the immune system and therefore does not lead to anaphylaxis (Gelinick et al., 2008). Food hypersensitivity is another commonly used term in the literature. It is used as an umbrella term for food allergy and non-allergic food hypersensitivity (Gelinick et al., 2008).

2.2.1 Diagnosis and Management

There is currently no cure for food allergies. Food immunotherapy (i.e., treatment by inducing an allergic response) has been tried, but it is only in its infancy (Otsu & Fleischer, 2012). Approaches which are currently being researched are still high risk, labour intensive, and not yet cost effective (Otsu & Fleischer, 2012). Fortunately, there is medication available that can delay the onset of symptoms of an anaphylactic reaction (Anaphylaxis Canada, 2011). Self-administered epinephrine is the most commonly used medication and it can save a life provided that it is administered immediately and emergency care is timely (Anaphylaxis Canada, 2011). The risk remains high, however, making dietary exclusion the only way for allergic individuals to avoid anaphylaxis. Responsible management of a food allergy involves reading food labels, taking extra precautions in food preparation, and being diligent in hand washing (Anaphylaxis Canada, 2011). Moreover, accidental exposure to food allergens is exacerbated by inconsistent and inappropriate food labelling and cross-contamination (Chow, 2011; Sheth et al., 2010; Vierk et al., 2007). This is complicated further by the wide variety of international foods that have changed eating habits, restaurant culture, and become a regular part of many people's diet (Sora et al., 2009). In addition, studies suggest that dietary exclusion can have a detrimental effect on

quality of life, particularly for families with young children at risk of anaphylaxis (Chow, 2011; Fenton et al., 2011; Gupta et al., 2008).

When it comes to children, the management of food allergies is particularly challenging. Most people experience an allergic reaction early in life when they are not yet equipped to manage their allergy. In fact, a study done in Montreal, Canada, found that 70-80% of children allergic to peanut have their first reaction between 14 and 24 months of age (Kagan et al., 2003). Children are also more vulnerable to experiencing an accidental allergic exposure because they are incapable of having any control over their environment (Fenton et al., 2011). Therefore, until the complex interplay between gene and environmental factors is deciphered and a cure is found, allergies will remain a public health concern.

The authors of a meta-analysis on the prevalence of food allergy found little consistency in self-reported rates of food allergy, making it difficult to draw conclusions (Rona et al., 2007). This finding could be the result of differences in study design, differences between populations, or a combination of both (Rona et al., 2007). Moreover, there is a lack of uniformity in criteria for diagnosis of a food allergy (Chafen et al., 2010). Double-blind, placebo-controlled food challenges remain the gold standard for diagnosis but the majority of studies use other diagnostic tests because they are much easier to implement (Rona et al., 2007). Therefore, estimates of food allergy prevalence that have been based on self-report should be interpreted with caution. Although the common perception of food allergies is that prevalence is on the rise, the evidence for this is unsubstantiated as only a limited number of studies have utilized a time-series design (Rona et al., 2007).

2.2.2 *Prevalence in North America*

With respect to prevalence of food allergy on a global scale, the majority of studies have been conducted in developed countries. The perception is that prevalence of food allergy is lower in Asia, South America, Africa, and the Middle East. However, studies are now calling for greater attention to food allergies in these regions and particularly in Asia, because of their rapid increase in affluence, urbanization, and adoption of a Western lifestyle (Boye, 2012; Gerez et al., 2010). As such, there is a wide variation of existing knowledge on food allergy making it necessary in this section to limit the scope to relevant studies from North America and Asia.

Depending on age and geographic location, food allergy prevalence has been reported to affect anywhere between 2-10% of the population (Sicherer, 2011). In Canada, it is reported that 7.14% of children and 6.56% of adults are food allergic, making the overall estimated prevalence 6.67% (Soller et al., 2012). The five most common allergens in the Canadian population are peanut, tree nut, sesame, fish, and shellfish (Ben-Shoshan et al., 2012a). Although these rates of prevalence are likely overestimated due to reliance on self-report and possible bias from non-response, these figures are relatively consistent with those from other developed countries (Soller et al., 2012; Vierk et al., 2007).

For example, the self-reported prevalence of food allergy in the U.S. is 9.1%, and 5.3% for respondents who were physician-diagnosed (Vierk et al., 2007). For American children, the estimated prevalence of food allergy is 8% (Gupta et al., 2011). Reported prevalence rates in Europe are more varied and the majority of them have been done in pediatric populations. A study of 10 European nations measured the prevalence of parent-reported food allergy to be 4.7% (Steinke et al., 2007).

As for demographic predictors of food allergy, education level, immigrant status, and birth place have been identified as significant in the Canadian population (Ben-Shoshan et al., 2012a). Households where the respondent had a postsecondary education were found more likely to report a food allergy (Ben-Shoshan et al., 2012a). In contrast, food allergies were less common in low income and immigrant households (Ben-Shoshan et al., 2012a). As a caveat to these findings, Canadians of lower socioeconomic status and immigrants were underrepresented in the study. The participation rate was also low (34.6%), causing a potential selection bias (Soller et al., 2012). Since the publication of these findings, a second round of data collection has been conducted to generate a sample that is a more accurate representation of the Canadian population. This study, entitled SPACE, is discussed in greater detail in Section 3.2. With respect to the U.S., a study on demographic predictors of food allergy has yet to be done (Ben-Shoshan et al., 2012a).

2.2.3 Prevalence in Asia

Prevalence of food allergy and other allergic diseases is highly variable within Asia itself. The common perception though is that prevalence of food allergy in Asia is low compared to the U.K., New Zealand, and Australia, since there are fewer reported incidences of anaphylaxis (Gerez et al., 2010). Still, prevalence of food allergy appears to be on the rise and it is speculated that it will become increasingly common in Asia just like asthma. This is particularly relevant to modernized regions of Asia such as Hong Kong where prevalence of food allergy is comparable to rates in North America. In a study from 2009, parent-reported prevalence of food allergy in Hong Kong was 8.1%, while the prevalence of physician-diagnosed food allergy was 4.6% (Leung et al., 2009a). The most recent epidemiological study from Hong Kong reports that prevalence of food allergy in children is 4.8% (Ho et al., 2012). More rigorous studies that will

use double blinded food challenges to diagnose food allergy in Hong Kong are already underway (Ho et al., 2012).

In studies of Singaporean school children, prevalence is also estimated to be 4-5% (Hill et al., 1997). However, prevalence rates differ between local and expatriate school children in Singapore, the major difference being that peanut and tree nut allergy are more prevalent in expatriates than locals (Shek et al., 2010). Moreover, shellfish allergy was more common among local Singaporean children (Shek et al., 2010). This agrees with the general consensus that seafood allergy (fish, mollusc, and crustacean) is more prevalent in Asia than in North America (Hajeb & Selamat, 2011; Hill et al., 1997). Unsurprisingly, this may be attributed to the fact that Asia has the highest rates of fish consumption in the world (Hajeb & Selamat, 2012). As a staple food in their diet, the first intake of seafood is typically very early in life (Hajeb & Selamat, 2012).

The result from Shek et al. (2010) which found that peanut and tree nut allergy was more common in expatriate children also agrees with the literature. Peanut and tree nut allergy are more infrequent in Asia than in North America and they are seen mostly in young children with multiple hypersensitivities or those who have a family history of atopic dermatitis (Chiang et al., 2007; Lao-araya & Trakultivakorn, 2012). Studies have attributed the differences in peanut and tree nut sensitivity to methods of preparation and consumption (Chiang et al., 2007). This has been supported by a small number of studies examining the effect of heat on peanut allergenicity (Beyer et al., 2001; Vissers et al., 2011). In North America, roasted peanuts are typically consumed, whereas in Asia, they are often eaten in boiled or raw form (Chiang et al., 2007).

Many allergens that are unique to Asia have also been identified and could be the result of dietary differences. Some examples include bird's nest soup in Singapore and China (Goh et

al., 1999), ant eggs in Thailand (Lao-araya & Trakultivakorn, 2012), and buckwheat in Korea (Oh et al., 2005; Yang et al., 2008).

With respect to food management, epinephrine auto-injectors are only accessible in some of the more modernized countries such as Singapore (Tham et al., 2008). However, prescription rates are still low due to low levels of awareness and lowered rates of anaphylaxis (Tham et al., 2008). In Thailand and the Philippines, epinephrine auto-injectors are not even available because of cost constraints (Jirapongsananuruk et al., 2007; Shek et al., 2010). In Asia there is also no legislation to enforce food labelling or precautionary statements (Gerez et al., 2010). Ingredient lists are mandated in some countries like Singapore, but common allergens do not need to be listed separately if there are traces of it in the food product (Gerez et al., 2010; Shek & Lee, 2006).

As more studies begin to report an increase in prevalence of food allergy in Asia, there is a growing need to recognize the importance of safety measures. Pragmatic guidelines for diagnosis and treatment are also needed, in addition to the availability of epinephrine auto-injectors and proper food labelling practices (Vichyanond, 2013).

2.3 Theoretical Context

2.3.1 A Social Constructionist Approach to Health

Social constructionism is a humanistic paradigm that seeks to uncover people's beliefs, values, and experiences as a means to understanding social phenomenon. It is a type of social theory that emphasizes the mediating role of social context on knowledge (Willis et al., 2007). From a health perspective, this means that a person's individual meaning of health and illness has been constructed from their everyday interactions, whether through conversations or encounters with others (Gatrell & Elliott, 2009; Willis et al., 2007). These interactions are

interpreted and acted upon to create a dynamic process. This process can be used to generate explanations and gain insight into health-related behaviour. Ultimately, the purpose of the social constructionist approach is to have an empathetic understanding of an individual's interpretation of their health and explain how it has been influenced by their perceived social reality (Berger & Luckmann, 1967; Gatrell & Elliott, 2009).

The social constructionist approach has been used to inform health research on a variety of topics, typically using qualitative methods. Some of these topics include the relationship between living in lower socioeconomic neighbourhoods and physical activity (Carroll et al., 2008), and the impact of asthma in young people (Rich et al., 2000) and ethnocultural communities (Rooney et al., 2011). These studies usually focus on a small group of purposefully selected individuals. For example, in a study of a residential area just outside of Brisbane, Australia, the investigators purposefully chose participants who came from affordable or government supported housing where entry is based on income criteria (Carroll et al., 2008). Their objective was to examine why individuals of lower socioeconomic status had reportedly less active and healthy lifestyles (Carroll et al., 2008). Through online blog entries, in-depth interviews, and focus groups, the phrases and narratives provided by participants revealed how the different social and living contexts through which they had travelled had instilled harsh and hostile barriers to feeling confident about both their body image and their ability to be physically active (Carroll et al., 2008). Negative feelings about self-identity were shaped over time as many of the participants had grown up in unsafe neighbourhoods, experienced child abuse, or had faced social exclusion as an adult (Carroll et al., 2008). The social constructionist approach allowed these individuals to share their experience in their own words, which was important for

establishing context. The investigators were able to pinpoint specific barriers to physical activity that would have been difficult to identify under a different paradigm.

A similar approach was effectively used to understand the views of South Asians with asthma in a study by Rooney et al. (2011). The researchers chose to focus on South Asians since they represent the largest ethnic minority group in the U.K. (Rooney et al., 2011). Participant beliefs, experiences, and perceptions on participating in research studies were explored through the use of focus groups (Rooney et al., 2011). During the focus groups, a broad slate of carefully chosen topics was discussed in order to reveal barriers and motivations to participate in research, as well as facilitators of successful recruitment (Rooney et al., 2011). It was found that personalized approaches to contact and communicate with participants would be better received than impersonal written approaches (Rooney et al., 2011). Barriers to participation in research included the stigma attached to having asthma as well as concerns with pharmaceutical trials (such as unfamiliarity with the research process, fear of potential side effects, etc.) (Rooney et al., 2011). These findings demonstrate that individual meanings of health are impacted by social experience.

A study by Rich et al. (2000) supports this further by stating that “although disease is a biologic phenomenon, illness is a socially constructed experience.” The biology of asthma may be well understood by clinicians, but how affected individuals perceive their asthma and cope with it is vital information that can be used to improve patient care (Rich et al., 2000). In summary, all of the illustrated examples above point to social constructionism as a powerful approach to evaluating the quality and effectiveness of health care services and policies.

2.3.2 *A Social Constructionist Approach to Food Allergy*

Qualitative work based on the social constructionist approach has also been undertaken in the context of food allergies. Many of these studies have explored the psychosocial impact of anaphylaxis – a life-threatening allergic condition often characterized by respiratory compromise, shock, and cardiovascular collapse in severe cases (Akeson et al., 2007; Ben-Shoshan & Clarke, 2011). To understand anaphylaxis better, researchers have sought the perspectives of food-allergic children (Avery et al., 2003; Fenton et al., 2011; Hu et al., 2005), adolescents (Akeson et al., 2007; Sampson et al., 2006), their parents (Akeson et al., 2007; Hu et al., 2005; Mandell et al., 2005), allergists (Xu et al., 2010), and the general public (Gupta et al., 2008; Sora et al., 2009), using an assortment of qualitative techniques.

A unique approach to using qualitative methods in food allergy research was the use of illustration in a study by Fenton et al. (2011). Children were asked to illustrate what it is like to live with a food allergy and explain their drawing (Fenton et al., 2011). This was followed by an in-depth interview where children were able to share how they felt about their school as a safe place (Fenton et al., 2011). Through this process, the children identified environmental and social barriers that led to exclusion from their peers (Fenton et al., 2011). Older children were also observed to have different coping strategies as they carry a greater emotional burden from their allergy than younger children (Fenton et al., 2011). The adolescents in the study described the transition involved in having their parents play a major role in managing their food allergy to taking on the responsibility themselves (Fenton et al., 2011). Responsibility was also a common theme in other studies of food-allergic adolescents.

Parents also play a major role in managing a food allergy. In a study that used in-depth interviews with adolescents and their parents, it was revealed that parents of anaphylactic

children can suffer from long-term psychological impact and anxiety as a result of their child's condition (Akeson et al., 2007). In addition, it is possible for the parent's anxiety to be transferred to their children, causing an effect on the entire family (Akeson et al., 2007). Mandell et al. (2005) echoed a similar sentiment when they likened the anaphylaxis experience of a family to being similar to adapting to a chronic illness. Thus, it is evident that food allergies have a significant impact on the everyday lives of affected individuals.

The social constructionist paradigm is an ideal approach that allows us to put ourselves in other's shoes in an attempt to understand, and ultimately address, the daily challenges and risks associated with having a food allergy. In this thesis, the social constructionist approach was used to uncover the lived experiences of food allergic individuals who are also new Canadians, specifically those of East and Southeast Asian heritage.

2.4 Perception of Food Allergy Risk

Food allergies are an emerging health concern that has gained greater attention in the Canadian media in recent years (Harrington et al., 2012a). This is an important trend that reflects the great uncertainty that surrounds the etiology of food allergy and its associated risks. However, studies suggest that there is now a gap between perceived and actual risk of food allergy; the public understanding of risk of food allergy is, in fact, inflated (Harrington et al., 2012b). Data from a national survey suggest that the average Canadian respondent estimated the prevalence of food allergy to be 30%, when the clinically-defined prevalence is only 7.5% (Harrington et al., 2012b). It is critical to recognize gaps in risk perception since people's understanding of public health issues can play a considerable part in informing policy, especially when understanding is shaped by media (Rachul & Caulfield, 2011; Slovic, 1987). Moreover, by

understanding factors that influence risk perception such as familiarity and personal ability to affect risk, policy-makers can anticipate how the public will respond (Kasperson et al., 1988).

One particularly interesting finding from Harrington et al. (2012b) is that immigrants who have lived in Canada for less than 10 years are more likely than non-immigrants to rate the risk of food allergy as “high” (OR: 2.51, 95% CI: (1.48,4.47)). Furthermore, the inverse relationship was found for immigrants who have lived in Canada for more than 10 years (Harrington et al., 2012b). Thus, the results reveal a strong relationship between perceived risk and time lived in Canada (Harrington et al., 2012b). The results also parallel the healthy immigrant effect which acknowledges immigrants as having better health status than non-immigrants at the time of arrival; over time, however, health status declines until it reaches a level on par with the native-born population (Asanin Dean & Wilson, 2010; Newbold, 2005). The healthy immigrant effect has been explored in the Canadian population, only to get mixed results (Asanin Dean & Wilson, 2010; Newbold, 2005). In the study by Asanin Dean & Wilson (2010), immigrants believed that the Canadian lifestyle could be both beneficial and detrimental to their health. Furthermore, declines in health were not attributed to changes in lifestyle, but rather the ageing process or the stress associated with migration (Asanin Dean & Wilson, 2010). Therefore, the evidence does not suggest that the relationship between perceived risk of food allergy and time lived in Canada is a result of the healthy immigrant effect. The evidence only supports the observation that new Canadians have a high perception of food allergy risk even though the prevalence of food allergy is reportedly less common in immigrant households in Canada (Ben-Shoshan et al., 2012a; Harrington et al., 2012b).

2.5 Food Allergy and Quality of Life

Studies suggest that the psychosocial impact of anaphylaxis on children and their families is significant (Akeson et al., 2007; Hu et al., 2005; Mandell et al., 2005). Findings also indicate that managing a food allergy and avoiding risk is extremely challenging, particularly when outside the home (Avery et al., 2003; Fenton et al., 2011; Sampson et al., 2006). This, too, can have a detrimental effect on quality of life.

In a study of food allergic children in Hong Kong, quality of life of parents was assessed using a questionnaire (Leung et al., 2009b). Findings indicate that food avoidance and having multiple food allergies impairs quality of life (Leung et al., 2009b). These two factors increase both the parents' burden in preparing safe foods for their child and the accompanying anxiety of a potential allergic reaction (Leung et al., 2009b). A quality of life survey has also been done as a comparative study in children (Avery et al., 2003). Through the use of quality of life questionnaires and photography (photovoice method), it was found that children with a peanut allergy reported a poorer quality of life than children with insulin-dependent diabetes mellitus (Avery et al., 2003). This was attributed to the fact that children with peanut allergy felt more threatened by potential hazards in their environment, leading to greater feelings of anxiety (Avery et al., 2003).

Similarly, an Australian study explored parental perceptions of dietary advice received upon their child's diagnosis of a seafood allergy and the consequences it had on family life (Ng et al., 2011). The results suggest that seafood allergy is a significant cause of anxiety and stress in families with an allergic child (Ng et al., 2011). Furthermore, parents were more likely to impose dietary restrictions that were more stringent than necessary; this observation is a possible reflection of high levels of anxiety in parents and has an adverse impact on quality of life (Ng et

al., 2011). The researchers concluded that avoidance of seafood may be more difficult than previously thought, especially since many of the children had experienced accidental exposure to seafood despite careful management (Ng et al., 2011).

Fenton et al. (2011) also examined the impacts of food allergy on quality of life by exploring barriers to safety for anaphylactic children in schools. For most children, the greatest barrier to their safety was people who were uninformed or misinformed about food allergies (Fenton et al., 2011). Anaphylactic children also face social isolation and exclusion which can result from being teased, being singled out for their condition, or having to miss out on school activities (Fenton et al., 2011). Parents of anaphylactic children also report feelings of isolation because they would rather not risk having their children socializing in households that do not have an allergic member in their family (Chow, 2011).

Finally, recent work from Ben-Shoshan et al. (2012b) demonstrates that the impact of food allergies on quality of life is not limited to directly affected individuals. Indirectly affected individuals, defined as those who have purchased or prepared food for an allergic individual outside the household, are reported to be at least as (or even more) vigilant in using precautionary statements to guide their purchasing decisions compared to directly affected individuals (Ben-Shoshan et al., 2012b). Ben-Shoshan et al. (2012b) state that indirectly affected individuals may experience a greater sense of responsibility when taking care of children other than their own; therefore, reinforcing that fact that the impact of food allergies can extend beyond those who are directly affected.

In summary, there are many barriers to managing a food allergy that can have a detrimental effect on quality of life. All family members in an allergic household, and even the community, have to be vigilant to ensure safety for the allergic member. There is a great

responsibility that comes with this, and anxiety from constant worry and assessment of the surrounding environment can lead to feelings of frustration and isolation. This thesis identifies the strategies used by new Canadians of East and Southeast Asian heritage to manage their food allergy. By having participants share their experiences about living with a food allergy through in-depth interviews, we can understand how they cope and how we can work towards improving their quality of life in both their country of birth and in Canada.

2.6 Qualitative Methods

Quantitative studies have pointed to a disparity in perceived and systematic prevalence of food allergies in new Canadians; however, it is qualitative methods that are best suited to examine how this disparity came to be in the first place. Qualitative methods allow researchers to interact with affected individuals to understand their point of view, making it an ideal approach to address the research objectives of this thesis. In addition, they allow for an intensive understanding of a phenomenon, as opposed to seeking a generalizable association between a determinant of health and health outcome. This is important to understanding how individual meanings of health have been constructed through social experience, according to social constructionism. Therefore, three qualitative techniques were used in this thesis: documentary analysis, key informants, and in-depth interviews. These three techniques complement one another and together they contribute to the trustworthiness of research results via triangulation (Farmer et al., 2006). Trustworthiness of data and its interpretation by the researcher are achieved through two means: confirmation and completeness (Breitmayer et al., 1993).

Confirmation is the use of multiple methods so that results can be compared to confirm or disconfirm findings (Farmer et al., 2006). When an observation is consistent across multiple qualitative techniques and/or sources, confidence is increased in the results (Farmer et al., 2006).

The term triangulation itself means to use two known points to plot a third; in other words, two techniques with their own set of advantages and weaknesses can be used to measure a single phenomenon.

Completeness is the combination of multiple methods with the purpose of revealing varied dimensions to the research interest. For example, interview guides for key informants differed from those used when interviewing participants with a food allergy. However, both sets of interview guides were created under the same research objectives. Together, completeness and confirmation ensure a credible account that should resonate with others who have had a similar experience and it should also be understandable to those outside the experience (Baxter & Eyles, 1997).

2.7 Chapter Summary

This chapter first described relevant literature pertaining to food allergy, its diagnosis and management, and its prevalence in North America and Asia. The social constructionist approach to health research was then described, demonstrating its use in contributing to our current understanding of food allergies. Studies on perception of food allergy risk were also examined; these studies have been fundamental to establishing the objectives of this thesis. In addition, a review of research on the impact of food allergies on quality of life validated qualitative methods as a valuable approach. These studies also point to a gap in knowledge that this thesis has been designed to fill. Finally, the qualitative techniques that have been chosen to ensure rigour in this thesis were discussed. In the next chapter, these techniques are described in detail as they were implemented to enable a deep understanding of a specific ethnocultural group and their experiences with food allergy.

CHAPTER THREE

Study Design & Methods

3.1 Introduction

While qualitative methods were first developed in the social sciences, their use in health research has increased over the last decade (Willis et al., 2007). Health research has benefited from the new insights provided by qualitative methods, especially in evaluating health policies and programs as well as patient needs and behaviour. Qualitative methods have also been used to assess the impact of anaphylaxis on quality of life, and therefore, they were implemented in this thesis to address the following research objectives:

- 1) To explore the policy context around food allergy for new Canadians
- 2) To understand how a specific ethnocultural group perceives food allergies and its associated risks
- 3) To appreciate how new Canadians manage and cope with food allergies

This chapter describes the use of three qualitative methods for data collection: documentary analysis, key informant interviews, and in-depth interviews. These methods complement one another, and together they allow for confirmation and completeness - two objectives in any rigorous qualitative research. In addition, this chapter gives an overview of the data used to inform participant selection. The ethical considerations made during the recruitment and interview stages are also discussed. Finally, the steps taken for analysis of the interview transcripts in QSR International's NVivo 9 are described.

3.2 Study Population

The results of a national cross-sectional survey entitled SPAACE (Surveying the Prevalence of food Allergy in All Canadian Environments) were used to inform the choice of study population. The SPAACE survey had responses from 6,403 households (50.2% response rate), each of them chosen through random selection of telephone numbers using electronic White Pages. Respondents were asked questions on allergy type, factors associated with food allergy (e.g., diet, atopic history, family atopic history, pregnancy), food labelling, attitudes towards environmental health risks, and demographic information (e.g., household income, education level) (Ben-Shoshan et al., 2012a; Soller et al., 2012). For the purpose of choosing an ethnocultural group to focus on for this thesis, questions on the respondent's country of origin, length of time lived in Canada (less *or* more than 10 years), and type of food allergy were considered.

From the results of the SPAACE study, it was evident that a substantial portion of new Canadians with food allergies come from Asia (Appendix A). In fact, 49.55% of the survey's participants (excluding individuals born in Canada) reported that they were born in an Asian country. Figure 1.1 shows that a large proportion of food allergic individuals who participated in the survey were from South Asia (n=975), Southeast Asia (n=651), and East Asia (n=385). As this thesis is part of a larger research program, there was already a group at the University of Toronto Mississauga who planned on conducting qualitative work with immigrants from South Asia. Therefore, new Canadians of East and Southeast Asian heritage were chosen as the study population. Southeast Asians have ancestral origin in the Philippines, Vietnam, Indonesia, Malaysia, Burma (Myanmar), Cambodia, Laos, Thailand, Singapore, and Brunei. East Asians include individuals from China, Hong Kong, Macau, Japan, Korea, Mongolia, and Taiwan.

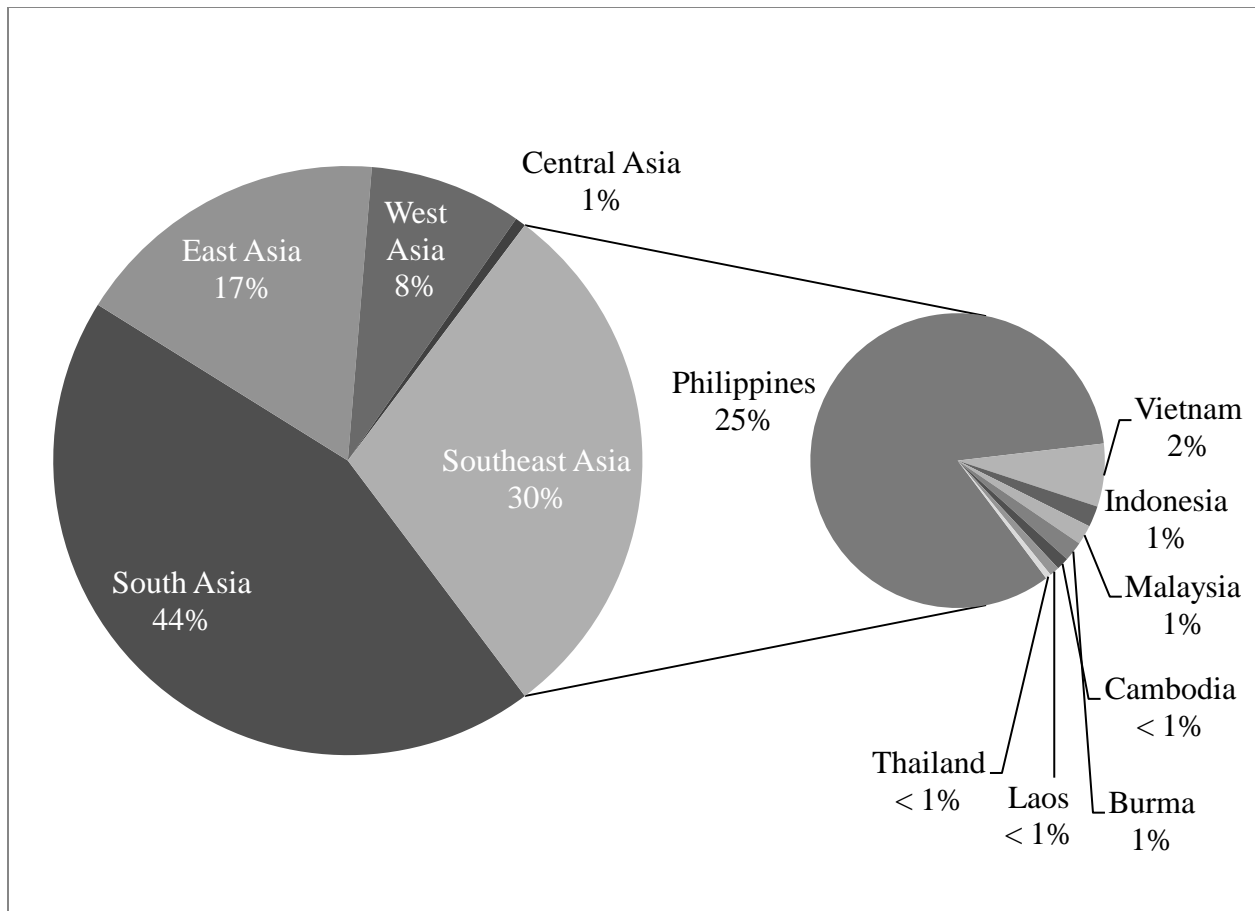


Figure 1.1: Proportion of Immigrants from Asia in SPAACE (n=2209)

3.3 Data Collection

3.3.1 Documentary Analysis of Policy Documents

A documentary analysis of policy and/or resource documents related to food allergy for new Canadians was conducted to establish context for this thesis as well as to address the first research objective. Documentary analysis is commonly used in health research because of its flexibility and wide application (Hsieh & Shannon, 2005). Any text data can be studied by focusing on characteristics of the language and its content (Hsieh & Shannon, 2005). This information adds an extra dimension to this thesis and sets the stage for the subsequent participant interviews.

For this analysis, key words such as *food allergy*, *new Canadian*, and *Canadian immigrant* were searched using the Google search engine. Relevant and publically available web pages were identified and screened to include only Canadian content related to food allergies. If a web page referred the reader to other Canadian sources on food allergies, those sites were also included in the analysis. Academic search engines geared towards researchers were not used, as the search was to be done from the perspective of a new Canadian looking for information about food allergies. Web pages were sorted into five categories for analysis: Federal, Provincial, School Board, Public Health, and Advocacy. This search for information pertaining to new Canadians with food allergies set the stage for the interviews with key informants and participants.

3.3.2 *Key Informant Interviews*

Key informants are commonly used in qualitative research because of their information-rich connection to a research topic (Crabtree & Miller, 1999). They often possess special knowledge of a particular culture that can help a researcher's own understanding. For this thesis, the goal was to recruit 3-5 key informants of varying expertise to participate in a semi-structured interview. The purpose of these interviews was to gain an understanding of how new Canadians might perceive their food allergy as well as any challenges they may face, and in short, to establish context for the participant interviews. Ethics clearance for conducting these interviews is in Appendix B.

By contacting various organizations in the Waterloo Region through telephone and e-mail, three key informants were successfully recruited; these individuals represent a constituency and include an allergist, public health nutritionist, and public health planner. Interviews with the key informants lasted approximately 30 minutes and were conducted in person. Each interview

covered topics specific to the key informant's work experience as outlined by the interview guides in Appendix C. The informants were also asked for their consent to have the interview digitally audio-recorded and transcribed verbatim for subsequent analysis.

Making connections with key informants proved to be a practical way to garner insight on food allergies. The establishment of a good working relationship with key informants helped build trust between the researcher and community members. Furthermore, the insights gained through the key informant interviews served as an excellent resource in preparation for the in-depth interviews with new Canadians.

3.3.3 Participant Interviews

Participant interviews were conducted with the purpose of capturing the views of new Canadians of Asian descent with either a) a physician-diagnosed food allergy of their own, or b) a member of their household who has a physician-diagnosed food allergy (e.g., mother of a food-allergic child). One on one, in-depth interviewing ensured a personalized approach to research which is better received by participants than written questionnaires (Rooney et al., 2011).

To be eligible for participation, the interviewee had to be 18 years of age or older, feel comfortable with speaking English, and have permanent resident status in Canada. In an ideal situation, participants should have been provided with a translator if requested. However, a translator was not an option to participants with limited English due to study constraints. It was also necessary for participants to have permanent resident status, since temporary residents do not fall under the definition of immigrants (Region of Waterloo, 2009). Abiding by the region's definition of immigrant was important for consistency and transferability of results. Furthermore, studies suggest that immigrant status can impact an individual's willingness to participate in

research (Lakes et al., 2012). Therefore, only permanent residents were eligible to participate in order to eliminate any potential biases.

3.3.3.1 Recruitment

Participants were recruited from Waterloo Region and the City of Toronto – two of the most populous and diverse places in Ontario, Canada. Most of the recruitment efforts targeted recent immigrants in Waterloo Region since this is where the research took place. The geographic region was expanded to include the City of Toronto to enhance recruitment. Waterloo Region is made up of three urban municipalities (Waterloo, Kitchener, and Cambridge) and four rural townships (North Dumfries, Wellesley, Wilmot, and Woolwich). It is one of the fastest-growing areas in Ontario and it has the 9th highest proportion of visible minorities of all Census Metropolitan Areas across Canada (Region of Waterloo, 2009). In addition, East and Southeast Asians are two of the most common visible minorities in the Waterloo Region (Region of Waterloo, 2009). Their population in Waterloo Region is predicted to continue to increase from 10.5% to 18.9-23.0% of the total population in 2031 (Region of Waterloo, 2009).

The City of Toronto, one of the most multicultural cities in the world, also has a large proportion of immigrants. In fact, half of Toronto's population of 1,237,720 individuals were born outside of Canada (City of Toronto, 2008). The Chinese are also one of the top five visible minority groups in Toronto as they represent 11.4% of the total population (City of Toronto, 2008).

Online advertisements were placed on Kijiji and forwarded through various organization email lists. A list of all the agencies that agreed to assist with recruitment is in Appendix D. Physical flyers were also distributed around the University of Waterloo (Appendix D). Once participants responded to the advertisements, they were screened for eligibility through telephone

or e-mail. Those who fit the criteria were asked to read a formal information letter and consent form (Appendix E). In total, 18 participants were recruited and interviewed over a three month period (November 2012 to January 2013).

Once participants gave their consent to participate (verbal or signed permission), a time and location was arranged at the participant's convenience. The participant's ability to choose a time and location was important since flexibility is a facilitator of successful recruitment of ethnic minorities (Rooney et al., 2011). In addition, participants who lived outside of Waterloo Region (n=9) had the option of doing the interview over the telephone. Those who did live in Waterloo Region (n=9) were interviewed in a carefully chosen public space to ensure a comfortable setting. Although in-person interviews are more traditional in qualitative research, Trier-Bieniek (2012) states that telephone interviews are equally participant-centered. Telephone interviews may even result in more honest data as many people are now used to "virtual" communication (Trier-Bieniek, 2012). Studies also suggest that there is no significant difference in quality of data between in-person and telephone interviews (Trier-Bieniek, 2012).

3.3.3.2 Interview Content

Participants were asked to complete a short demographic questionnaire (Appendix F). The information gathered from the participants is displayed in Table 3.1.

Table 3.1: Participant Characteristics

	Gender	Age Group	Birth Place (place raised, if different)	Years Lived in Canada	Highest Educational Degree	Current or Most Recent Occupation	Allergic Person in Household	Allergy	Age of Diagnosis (years)
1	female	22-25	Hong Kong	<10	Bachelors degree	Student	self	lychee, lobster	8
2	female	26-30	Thailand	<5	Bachelors degree	Engineer	self	salmon, jack fruit, durian	19
3	male	22-25	Panama (Hong Kong)	<20	Bachelors degree	Student	self	shellfish, peanut	10
4	female	31-40	China	<10	High School	Admin clerk	son	peanut, beans	2
5	female	41-50	Philippines	<10	Bachelors degree	Cleaner	daughter	egg, milk, peanut	1 month
6	female	31-40	Vietnam	21+	Bachelors degree	Financial advisor	son	peanut, cashew	6
7	male	18-21	Philippines	<20	High School	Student	self	shrimp, shellfish	12
8	male	22-25	Philippines	<20	Bachelors degree	Merchandiser	self	blueberries, shellfish	19
9	female	18-21	Hong Kong	<10	High School	Student	self	shellfish, selected fish	7
10	female	31-40	Philippines	<5	Bachelors degree	Home maker	self	shellfish	10
11	male	22-25	Thailand	<20	Bachelors degree	Designer	self	fish, shellfish	15
12	female	22-25	China	<20	Bachelors degree	Student	self	shrimp, prawns	10
13	female	22-25	China	<5	High School	Student	self	mango	17
14	female	22-25	China	<5	High School	Student	self	peanut, beans, fish, shrimp	11
15	female	18-21	India (Japan, Singapore)	<5	High School	Student	self	peanut, shellfish	11
16	female	26-30	Malaysia	<5	Bachelors degree	Dietetic intern	self	shrimp	15
17	female	18-21	China	<20	High School	Student	self	shellfish	13
18	female	41-50	Hong Kong	21+	Masters degree	Software developer	son	egg, wheat, tilapia	21 months

Some notable facts about this sample include: a) participants either had an allergy of their own (n=14) or they were a mother with an allergic child (n=4), b) the most common allergen was shellfish (n=10), and c) most participants were over 5 years old when their allergy was diagnosed (n=15). In addition, just over half of the participants have lived in Canada for less than 10 years (n=10). The participant's background with respect to length of time lived in Canada and birth place is shown in Figure 1.2.

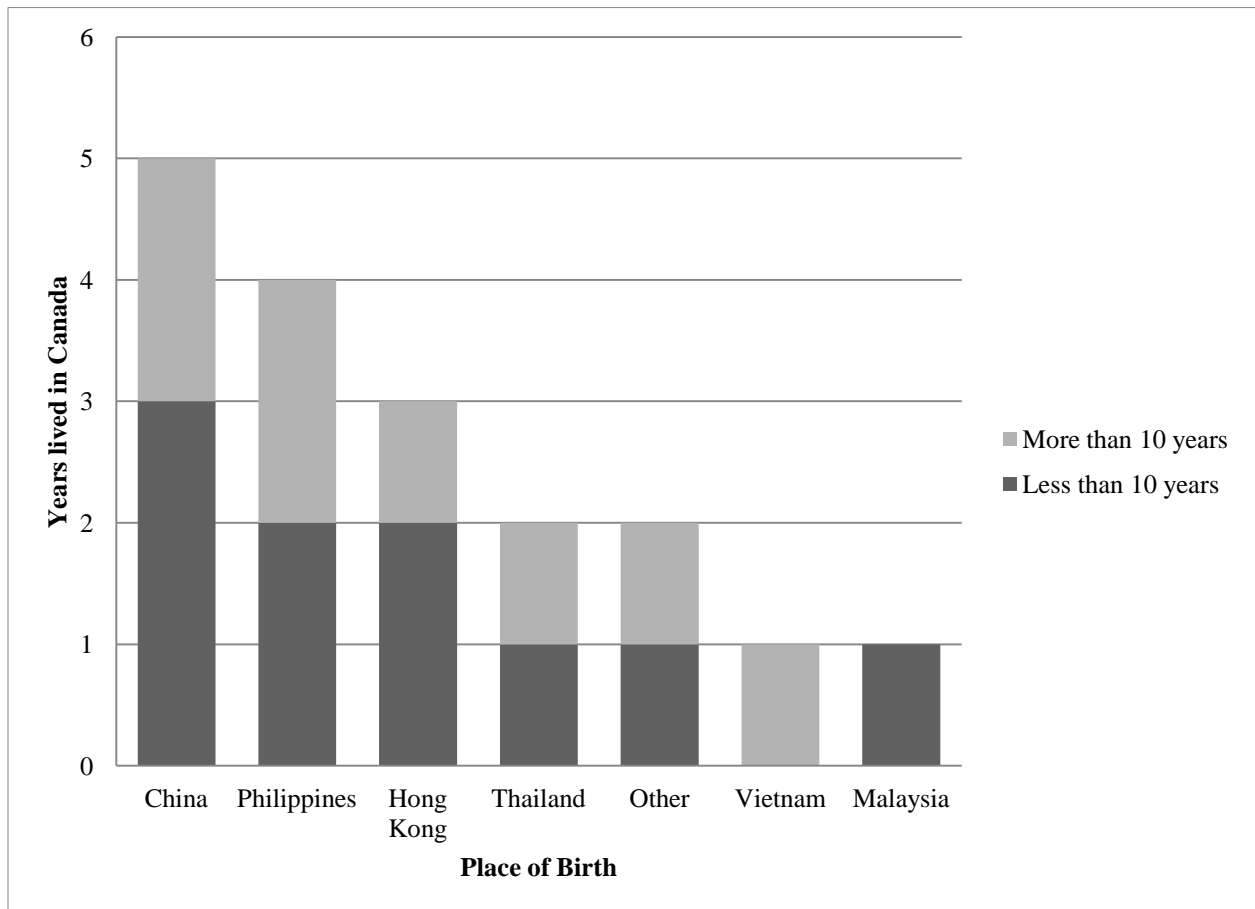


Figure 1.2: Participant Background

Interviews ran for approximately 30 minutes in length. Similar to the interviews with key informants, an interview guide was used to lead the discussion in a conversational manner (Appendix G). The interview guide was created with the purpose of understanding how new

Canadians perceive their food allergies and to also identify any coping strategies and/or barriers new Canadians may face when managing their food allergy. A variety of topics were covered, including feelings associated with the participant's first reaction and diagnosis, the level of support they received from family and friends, prior experience with food allergies before moving to Canada, and the types of sources they have gone to for information concerning their allergy. Each interview was conducted by the same researcher and digitally audio-recorded for transcription. At the end of the interview, the researcher summarized the discussion and explained their interpretation of the interview. Participants were asked if the summary was adequate and they were encouraged to add anything they felt was missing. This process served as an informal method of member checking.

Lastly, participants were given the option to share their e-mail address after the interview. A letter of appreciation and a summary of the thesis results were sent electronically to those who made this request and provided an e-mail address.

3.4 Data Analysis

Participant interviews were conducted until saturation was reached. That is, until the point where no new themes or disconfirming evidence emerged during the interview process (Crabtree & Miller, 1999). Upon completion of all the interviews, the digital recordings were transcribed verbatim for subsequent thematic analysis in QSR International's NVivo 9. A theme code set was created based on the objectives of this thesis and the interview guides (through deductive reasoning), and the interview transcripts (inductive reasoning). As each transcript was coded, the theme code set was modified and refined in order to capture all the nuances in the data set. The theme code set (Appendix C) was also tested for inter-rater reliability with a second coder at the graduate level, with two interview transcripts. An agreement level of 81% between

the two coders was achieved, after resolving any conflicts. An intra-rater reliability test was also conducted to ensure a degree of consistency of results as all of the coding and interpretation of the data was done by a single researcher. An agreement level of 82% was achieved. The agreement formula from Miles and Huberman (1994) was used for both tests.

The inter- and intra-reliability tests are an example of measures used to establish rigour in qualitative research. In total there are four existing criteria for evaluating the analysis of qualitative research, as established by Lincoln & Guba (1985). Each of these criteria was taken into consideration in the design of this thesis. The first criterion is *credibility* - the degree to which the research presents an accurate representation of experience (Baxter & Eyles, 1997). Credibility was achieved by careful screening of participants to make sure they fit the strict eligibility criteria. Credibility was also strengthened by the use of triangulation, as described in Section 2.6, and member checking.

Transferability, the second criterion, refers to the degree to which findings apply in contexts outside of the study (Baxter & Eyles, 1997). This is of lesser concern in qualitative research; however, it is hoped that the experiences captured and presented in Chapter 4 will be relatable to other ethnocultural groups who are new to Canada and affected by food allergy.

Thirdly, *dependability* is the degree of consistency of results. Dependability has been achieved by having a) all interviews digitally audio-recorded, b) the same researcher guide all interviews with key informants and participants, and c) the same researcher code and interpret all the data.

Finally, the fourth criterion *confirmability* refers to the degree to which findings represent the true account of the respondents and not the biases or interests of the researcher. As the primary researcher, I would like to state that I have been indirectly affected by food allergies. I

have witnessed some of the challenges that anaphylactic children and their parents face on an everyday basis, from the perspective of a friend and caretaker. I am also a Canadian-born Chinese. Although I have not experienced what it is like to migrate to a new country, I am very familiar with the hardships my grandparents and mother faced when they first moved to Canada. It is hoped that these experiences have allowed members of the community to feel comfortable in sharing their own stories with me during the course of this thesis.

3.5 Chapter Summary

This chapter began by revisiting the social constructionist approach and the groundwork it has laid for the three research objectives and the chosen methodology for this thesis. The results from SPAACE, a cross-sectional survey of all of Canada, were used to inform the decision to focus on new Canadians of East and Southeast Asian heritage. A documentary analysis and interviews with three key informants were conducted to establish context. Individuals with personal experience with food allergies were also recruited to participate in in-depth interviews, the primary source of data in this thesis. Together, these three methods for data analysis add credibility to the results through triangulation. The four criterion established by Lincoln and Guba (1985) were also used to evaluate the level of rigour in the data analysis.

CHAPTER FOUR

Results

4.1 Introduction

This chapter presents the results of the analysis performed to address the following research objectives:

- 1) To explore the policy context around food allergy for new Canadians
- 2) To understand how a specific ethnocultural group perceives food allergies and its associated risks
- 3) To appreciate how new Canadians manage and cope with food allergies

Objective 1 was addressed through an analysis of policy and/or documents and three key informant interviews. The analysis of the key informant interviews contributed to objectives 2 and 3, as they helped to inform the types of questions asked in the in-depth interviews with affected individuals. The results of the analysis of the participant interviews are organized around four major themes: perceived prevalence, risk perception, management and coping, and quality of life. The first two themes address objective 2 as they are related to perception. Objective 3 is reflected in the themes of management and coping of food allergies and its impact on quality of life. Tables are used to show the frequency of themes. Direct quotations are used to punctuate common themes emerging from the data.

4.2 Policy Context

4.2.1 *Documentary Analysis of Policy Documents*

Publically available web pages (n=21) were analyzed to establish a policy context relevant to food allergies for new Canadians (Table 4.1). The web pages were sorted into five categories based on the source: Federal, Provincial, School Board, Public Health, and Advocacy.

Sources containing a section or separate web page specific to food allergies are indicated in Table 4.1 with the greater-than sign (>). The greater-than sign represents the number of “clicks” required to get to the food allergy page from the home page.

None of the searched web pages contained information specific to new Canadians, including web pages of Health Canada and the major allergic advocacy groups. Furthermore, Table 4.1 indicates that many of the resources are not easily accessible, given the number of “clicks” it takes to find relevant information. For example, Health Canada has a comprehensive guide to food allergies, but it is spread over multiple web pages such as *Allergen Labelling*, *Food and Nutrition*, *Severe Allergic Reactions*, and *Food Allergies and Intolerances*. Moreover, Health Canada’s web pages are only available in English and French. While this fulfills the requirement of the Official Languages Act, it is not helpful to new Canadians who are learning English as a second language.

Table 4.1 Searched policy and resource web pages for food allergy content

Federal	Health Canada > Food & Nutrition > Food Labelling > Allergen Labelling ¹	http://www.hc-sc.gc.ca/fn-an/label-etiquet/allergen/index-eng.php
	Health Canada > Food & Nutrition > Food Safety > Food Allergies and Intolerances	http://www.hc-sc.gc.ca/fn-an/securit/allerg/index-eng.php
	Health Canada > Healthy Living > It's Your Health > Food and Nutrition	http://www.hc-sc.gc.ca/hl-vs/iyh-vsv/food-aliment/allerg-eng.php
	Health Canada > Healthy Living > It's Your Health > Medical > Severe Allergic Reactions	http://www.hc-sc.gc.ca/hl-vs/iyh-vsv/med/allerg-eng.php
	Canadian Food Inspection Agency (CFIA) > Food > Consumer Centre > Food Safety Tips > Labelling, Food Packaging and Storage > Food Allergies and Allergen Labelling Information for Consumers	http://www.inspection.gc.ca/food/consumer-centre/food-safety-tips/labelling-food-packaging-and-storage/food-allergies/eng/1332442914456/1332442980290
Provincial	EatRight Ontario (Dieticians of Canada) > Food allergies/intolerances	http://www.eatrightontario.ca/en/Articles/Food-allergies-intolerances/Food-allergies---Intolerances.aspx
	Sabrina's Law, 2005	http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_05s07_e.htm
	Online Anaphylaxis Training Prevention First	http://www.eworkshop.on.ca/cfm/edu/anaphylaxis/
	TeachNutrition.org > Teaching Nutrition > Nutrition FAQ > Food Allergies and Intolerances	http://ontario.teachnutrition.org/teaching-nutrition/pages/nutrition-questions/allergies-intolerances.aspx
School Board	Waterloo Region District School Board	http://www.wrdsb.ca/
	Waterloo Catholic District School Board	http://www.wcdsb.ca/
	Waterloo Catholic District School Board Newcomer Reception Centre	http://newcomer.wcdsb.ca/welcome.html
Public Health	Region of Waterloo Public Health > Nutrition > School Resources	http://chd.region.waterloo.on.ca/en/healthylivinghealthprotection/schoolresources.asp
	Region of Waterloo Public Health > Child Health – General Topics > Allergies to Food	http://chd.region.waterloo.on.ca/en/childfamilyhealth/allergiestofood.asp
Advocacy	Anaphylaxis Canada	http://www.anaphylaxis.ca/
	Nutrition for Learning	http://www.nutritionforlearning.ca/
	Canadian Anaphylaxis Initiative	http://cai-allergies.ca/
	Allergy Asthma Information Association (AAIA)	http://www.aaia.ca/en/index.htm
	Allergic Living Magazine	http://allergicliving.com/
	Canada Safety Council > Allergy Safe Schools	https://canadasafetycouncil.org/campaigns/allergy-safe-schools
	Allergy Safe Communities	http://www.allergysafecommunities.ca/pages/default.asp

¹ Greater-than sign (>) represents number of “clicks” required to get from website home page to food allergy content.

4.2.2 *Key Informant Interviews*

The key informants include an allergist, public health nutritionist, and public health planner from the Waterloo Region. Semi-structured interviews were conducted using the interview guides in Appendix C.

With respect to the regional allergist, interview content ranged from characteristics of the allergist's private practice, knowledge of food allergy trends and treatment strategies, and observations from professional experience with patients who are Canadian immigrants. These patients include new immigrants with asthma and/or allergies. It is estimated that 5-7% of the allergist's practice consists of visible minorities who have immigrated to Canada, including East and South Asians, Africans, Hispanics or Central Americans, South Americans, and Eastern Europeans. The vast majority of these individuals are first generation. It is suspected that the prevalence of food allergies in Waterloo Region is consistent with other communities in Canada, although it is possibly a bit higher. Incidence of peanut allergy has increased noticeably during the allergist's career in the Waterloo Region.

From past experience, the allergist has noticed that new Canadians are most concerned with receiving confirmation of their allergy and getting reassurance that their problem is not life-threatening. While the diagnosis process is very straightforward, it can be difficult to educate patients about how to avoid a reaction as well as the importance of using epinephrine in the form of an Epi-Pen. Moreover, the allergist has had experiences where the patient needed convincing that their food allergy is a real and serious issue:

Understanding what the issue is, is tough enough for patients that have grown up in Canada. To really appreciate and understand what a food allergy is, what it involves, and the potential risks, I think for immigrants it is even tougher because you know in most countries where they have immigrated from, allergy didn't exist. Or if it did exist, it was a really, really small issue.

(Key Informant 1 - *Regional Allergist*)

When directing patients to information on food allergies, the allergist uses reliable websites such as those by Health Canada, the Allergy Asthma Information Association (AAIA), and Anaphylaxis Canada. The allergist was unaware of any educational materials for new Canadians that are being widely distributed. Although the allergist has noticed an increase in awareness and knowledge of food allergies amongst immigrant patients, the onus to avoid certain foods lies heavily on the allergic individual. One of the challenges to this is ensuring that the information given to patients is accurate and easy to understand:

As allergists, I think we have to get that information out, make the diagnosis, and then, if the information is available, direct our patients to where they can get that information. Obviously the Internet would be the easiest place to go. I think if we had patient information that we could trust in different languages that could be quite helpful in terms of informing. I think they can find that information [on their own], but the reliability is hard to gauge based on the fact that we won't be providing it.

(Key Informant 1 - *Regional Allergist*)

This allergist believes that raising awareness amongst immigrants will probably have to be done piecemeal in each ethnocultural group.

In the second key informant interview, a public health nutritionist described the challenges that come with shaping a school environment that is healthy for students, including those with food allergies. Public health nutritionists are made available to parents as a resource if there is an allergic child attending the school. The public health nutritionist has never been contacted by a parent who is also a new Canadian.

Public health nutritionists are also sought by school principals for guidance on creating a safe environment for an allergic child. The public health nutritionist directs principals to trustworthy resources such as the Anaphylaxis Canada website, the online guide to anaphylaxis in schools by the Canadian Society of Allergy and Clinical Immunology, and/or the “e-

workshop” on anaphylaxis that is provided by the Ontario Ministry of Education and Télé-Française d'Ontario (TFO). The public health nutritionist’s responsibility is to advise the principal about precautions that can be taken by the school in order to protect the allergic child, although, it is ultimately the principal who decides which actions are appropriate to take. In the public health nutritionist’s experience, there is a wide variation in the level of precaution that is taken. Some school principals will place an outright ban on allowing the allergen in the classroom, whereas others will allow the allergen to be consumed in the classroom as long as there is regular hand washing and no sharing of foods.

With respect to improving the management of food allergies in schools, the public health nutritionist has several concerns. First of all, placing bans on foods in schools can be very restrictive, making it difficult for people to find food alternatives, especially if cost is a concern to lower income households. A restrictive diet can also make it more difficult to ensure that children are meeting their nutritional needs. Furthermore, the public health nutritionist is concerned about how allergic children are being perceived by their peers, especially if an incident gets reported in the media.

With these concerns, the public health nutritionist believes that the school boards should play a larger supporting role when it comes to managing food allergies:

I think the school boards should have more of an overview of what the protocol is and that every school follows this example. That is what I believe should be done, just because then the principal probably feels better about the decision. Things are always going to be a little bit different depending on the child, but clear steps that were outlined by the school board would be a step towards making things better.

(Key Informant 2 - *Public Health Nutritionist*)

As an educator, the public health nutritionist believes that it is important that schools are giving out accurate information about food allergies. Even with Sabrina’s Law, a law created to address

anaphylaxis in schools (Ontario Ministry of Education, 2005), current messages and practices regarding school safety and health are not always consistent within the same school board.

Ultimately, school principals are responsible for deciding how food allergies should be managed within the school and this can lead to differing courses of actions (e.g., sending out food lists to parents vs. providing parents with Epi-Pen training).

In the third key informant interview, a public health planner described Waterloo Region's Work Region Peer Program. The Peer Program has been running for 25 years and it is completely funded by Waterloo Region. The Peer Program consists of fifteen neighbourhood sites in the Waterloo Region. There are two volunteers from each neighbourhood site who receive training in two streams of work – positive parenting and nutrition. The volunteers act as a liaison between people working in public health and the neighbourhoods themselves. It is estimated that approximately 4,000 people are reached by the Peer Program each year. Many of the families involved are low-income households with young kids. It is estimated that recent immigrants and refugees make up 15-25% of the people in the Peer Program, depending on the neighbourhood site.

For discussions surrounding food, the Peer Program's focus is on healthy eating that is also cost effective. The public health planner expressed that food allergies are sometimes brought up in discussions amongst the volunteers and members of their neighbourhood, but it has never been an area of focus. From the public health planner's experience, new Canadians are most interested in integrating themselves into a Canadian lifestyle by adopting a North American diet:

Food is such a central piece; it is almost equal to language. People are comfortable in their own ethnic cultural groups to eat their own food, but when you want to integrate, especially when it comes to children, you

know, taking their lunch bags [to school] or whatever, there is a lot more pressure to adapt.

(Key Informant 3 - *Public Health Planner*)

Unfortunately, new Canadians are also more likely to adopt an unhealthy diet after moving to Canada because of cost and convenience. The public health planner believes that food allergies are not a primary concern amongst new Canadians because of the more immediate challenges they face when they move, such as finding employment.

Finally, the public health planner recognizes that food allergies may deserve greater attention in the Peer Program in the future. The public health planner, also an immigrant to Canada, was skeptical about the possible severity of food allergies until it became a personal issue:

It was quite a learning curve, nut free environments and all that. It took me a while to figure out and [accept that], yes, this is an issue.

(Key Informant 3 - *Public Health Planner*)

4.3 Participant Background

Results from the participant interviews are reported in the following sections. This first sub-section establishes the participant's immigration experience as well as their first personal encounter with food allergies.

The participants' reasons for immigrating to Canada are reported in Table 4.2. The majority of them moved to Canada for a better education (n=12) and improved quality of life (n=7).

Table 4.2: Reasons for immigrating to Canada

Reason	Number of participants (% of the total)	Mentions (% of the total)
Education	12 (67)	13 (50)
To join family	5 (28)	5 (19)
Occupation	1 (6)	1 (4)
Quality of life	7 (39)	7 (27)
Total	18* (100)	26 (100)

* This is not equal to the sum of the numbers in the column due to multiple responses

Table 4.3 summarizes the participant's first allergic experience. The four mothers who were interviewed were asked to describe the first time their child had an allergic reaction.

Table 4.3: First allergic experience

Source	Number of participants (% of the total)	Mentions (% of the total)
Symptoms	Hives	7 (39)
	Rashes	7 (39)
	Restricted airway	6 (33)
	Swelling	6 (33)
	Other (e.g., Itchiness)	10 (56)
Severity	No medication required	5 (28)
	Physician-administered medication	5 (28)
	Hospitalization	4 (22)
	Anaphylactic	5 (28)
Diagnosis	Self ²	5 (28)
	Nurse	1 (6)
	Physician	7 (39)
	Allergist	9 (50)
Diagnostic Test	Skin prick test	7 (39)
	Blood test	4 (22)
	Other	2 (11)
Feelings Associated with 1 st Reaction	Surprise	12 (67)
	Scared	3 (17)
	Quick acceptance	5 (28)
	Slow acceptance	4 (22)
	Disappointment	7 (39)
	Relief	2 (11)
Total	18* (100)	158 (100)

* This is not equal to the sum of the numbers in the column due to multiple responses

² Participant's allergy has not been confirmed by a diagnostic test.

Participants were asked to describe the symptoms they experienced to gauge the level of severity of their condition. Participants who fell under the category “Self” have not had their allergy confirmed by a diagnostic test (n=5). In some cases they have not felt a need to have their allergy confirmed because a family member in their household has a similar allergy.

Participants were also asked to describe the emotions and feelings they experienced when they had their first allergic experience. Many of them were surprised or even shocked to learn of their allergy (n=12), especially if they did not have any relatives in their immediate family who had a similar condition.

At first we were kind of surprised. Like it wasn't really believable because like I said, almost my whole life up to that point I was eating shrimp, seafood, and it was fine. Like my parents cooked it fine. It was one of my favourite foods, and the one day it happened, we were like really shocked. (Participant 11- *male from Thailand, <20 years in Canada, allergic to fish and shellfish*)

Yea, I was actually quite surprised and so were my parents because we had been around people with allergies before, like my friends and stuff, but none of them had such a severe reaction ... And especially because it was so unexpected at such a young age. I don't know, it is not common, so yea, surprised was one thing. Scared was another too. (Participant 15 - *female raised in Singapore and Japan, <5 years in Canada, allergic to peanut and shellfish*)

Yea we were surprised about the peanut [allergy] and the level of severity. I know he has had a chocolate bar before with peanuts. He has never had a reaction because he doesn't like nuts and he spat it out, but I know he has had [peanuts] in his mouth. So that was why we were so surprised to have that diagnosis ... Never in our family history I think have we had or heard of that, so yea I am surprised like for my child to have one. (Participant 6 - *female from Vietnam, 21+ years in Canada, son is allergic to peanut and cashew*)

Almost half of the participants also felt disappointment when they were diagnosed with their allergy (n=7). They either found it difficult to give up a food they liked or they were disappointed that they could have prevented previous reactions had they known before.

I guess when you accept it, it is easier to move on even though it was still a bit hard because yea like I say, it is a favourite food of mine. So giving it up was pretty difficult.

(Participant 11 - *male from Thailand, <20 years in Canada, allergic to fish and shellfish*)

I think when I first heard about it, I was kind of, I would say like a little bit like disappointed that I didn't find out earlier that I was allergic to shrimp and then I was like thinking of how many like rashes I could have avoided from shrimp.

(Participant 16 - *female from Malaysia, <5 years in Canada, allergic to shrimp*)

A mother also expressed the sadness she felt when her son was diagnosed:

I would just feel sad, like I just think that it is a kind of sickness. I just feel it is a misfortune right, why do we have a son that has food allergy? Why other people don't have such problem, right? I just feel it is sad. I just kind of accept the fact. I have to face it, right?

(Participant 4 - *female from China, <10 years in Canada, son is allergic to peanuts and beans*)

In summary, there is variation within the sample in terms of participant's allergic severity and also the process they went through when diagnosed. However, initial feelings about having a food allergy are very similar amongst all the participants. Although some of them had an easier time accepting that they needed to avoid certain foods from that point on, others took longer to accept the seriousness of their allergy and the subsequent changes they would need to make to their lifestyle.

4.4 Prevalence, Perception, and Experiences

The rest of the interview content has overriding themes of prevalence, perception, and experiences. Each theme is explored below as a means to address research objectives 2 and 3.

4.4.1 Perceived Prevalence

One of the predominant perceptions regarding food allergies is that prevalence is lower in Asia than it is in North America (Gerez et al., 2010). Current evidence supports this

perception, as reported in Section 2.2.3, although it is speculated that prevalence is increasing in both places. This perception rang true with participants as 83% of them thought that food allergies were less common in their birth place (Table 4.4). The one participant who thought that food allergies were less common in Canada was raised in Singapore.

Table 4.4: Perceived prevalence of food allergy in birth place

Perceived Prevalence	Number of participants (% of the total)	Mentions (% of the total)
Lower	15 (83)	24 (86)
Same	2 (11)	3 (11)
Higher	1 (6)	1 (3)
Total	18 (100)	28 (100)

Participants shared their observations that supported this view, many of which were related to people in their own social circle, media reporting, and policies in schools.

Well I realized especially like in grade four and grade five, all my friends could not eat peanuts, so we couldn't even bring peanuts to school, so that is when I realized, oh food allergies are pretty common here in Canada. Whereas I never really thought about it back in the Philippines.
(Participant 7 - male from Philippines, <20 years in Canada, allergic to shrimp and shellfish)

Yea I think when I was growing up I didn't know many people even with like peanut allergies. It was not common at all to have. And so I think that is one of the reasons why I didn't look to food to be an allergy until I was in my teens.
(Participant 16 - female from Malaysia, <5 years in Canada, allergic to shrimp)

Allergies seem more common here, and I think that Canadians, their food allergies are more serious, because in Hong Kong I don't hear anybody with food allergies would die. Mostly like skin allergy, because people here it is like if they consume some sort of food they can't breathe, and then they die.
(Participant 9 - female from Hong Kong, <10 years in Canada, allergic to shellfish and selected fish)

It is a lot rarer in China. Over here there is a lot of emphasis [on it], like one of the first things you learn in school is don't bring any peanuts. You don't find that in China.
(Participant 12 - female from China, <20 years in Canada, allergic to shrimp and prawns)

Many of the participants held similar views on perceived prevalence, even if they were from different countries in Asia. Their perception is unsurprising as it agrees with the current evidence on prevalence of food allergy in Asia (see Section 2.2.3).

4.4.2 Risk Perception

Similar to perceived prevalence, 44% of participants who commented on risk perception reported that the risk of food allergies in their birth place is lower than it is in Canada. With respect to the perceived etiology of food allergies, 78% of the participants stated that they did not know why they are allergic (Table 4.5). One mother tried to think of any differences she made to her lifestyle during her second pregnancy. Her older daughter does not have a food allergy, whereas her younger son is anaphylactic:

I am trying to think “did I do anything different with my second pregnancy than with my first?” My daughter has nothing, yet [my son] had all the eczema, and everything to go with it ... It is a mystery.
(Participant 6 – female from Vietnam, 21+ years in Canada, son is allergic to peanut and cashew)

A few participants, however, suspected that their allergy was partly a result of genetics because of other known family members who have food sensitivities (n=7). All participants were specifically asked whether or not they have any relatives, immediate or extended, with a food allergy. Surprisingly, one participant who did not have any relatives with a food allergy simply described herself as having “bad genes”:

I don't know because I would say I just have bad genes, well I have three other brothers. I am the only girl in the family, so I don't know why it is just carried among females. It could also be related to eczema, because I had that when I was young too.
(Participant 16 - female from Malaysia, <5 years in Canada, allergic to shrimp)

Table 4.5: Perceived etiology of food allergy (personal)

Type of Etiology	Number of participants (% of the total)	Mentions (% of the total)
Diet	1 (6)	1 (2)
Genetics	7 (39)	26 (48)
Unknown	14 (78)	25 (46)
Other	2 (11)	2 (4)
Total	18* (100)	54 (100)

* This is not equal to the sum of the numbers in the column due to multiple responses

Participants were also asked about the etiology of food allergies from a population perspective (Table 4.6). Interestingly, their views on etiology were quite different when they were no longer discussing their own personal allergy.

Table 4.6: Perceived etiology of food allergy (general population)

Type of Etiology	Number of participants (% of the total)	Mentions (% of the total)
Diet	5 (28)	5 (38)
Genetics	3 (17)	4 (31)
Hygiene Hypothesis	3 (17)	3 (23)
Other	1(6)	1 (8)
Total	12 (68)	13 (100)

Participants cited diet as a possible risk factor for food allergies, since several of them mentioned that Canadians consume more processed foods (n=5).

It might be because Chinese people eat everything, so from their ancestry they kind of don't have those allergies, because they start to eat anything like from years ago, but here people only eat certain kinds of food. They don't eat animals, like dogs and stuff, and so it is really hard to say. I don't know.

(Participant 14 - female from China, <5 years in Canada, allergic to peanuts, beans, fish, and shrimp)

Maybe it is the way the food is processed here, or maybe it is the way the, I mean if I were to speculate maybe it is like in terms of shrimp, it is the [Canadian] waters in which they live here as opposed to waters in Thailand like the rivers where it might be a bit more clean, but again that is just speculation.

(Participant 11 - male from Thailand, <20 years in Canada, allergic to fish and shellfish)

I think it is partly because of the diet. Maybe for the case of peanut allergies, it has something to do with the kid's protein intake when they

were growing up. Yea I think it is mostly because of the diet, and just the upbringing is a bit different, and all those things factor into higher cases of food allergies.

(Participant 7 - male from Philippines, <20 years in Canada, allergic to shrimp and shellfish)

Although some responses alluded to environmental factors as well, such as the previous quote from Participant 11 on water quality, fewer than expected participants referred to the hygiene hypothesis³ as an explanation for a higher prevalence of food allergies in Canada (n=3).

I haven't thought that much about it, but now you know it is because people are raised in a much cleaner environment here, so I guess they don't develop the, I don't know the same resistance to allergens.

(Participant 12 - female from China, <20 years in Canada, allergic to shrimp and prawns)

Another interesting outcome is that views on etiology differed when participants were speaking about their own allergy as opposed to others. For example, 78% of participants could not identify why they have a food allergy (Table 4.5). In contrast, participants cited examples related to diet, genetics, and the hygiene hypothesis to explain why people other than themselves develop food allergies (Table 4.6). This may be due to the participants' unfamiliarity with food allergies, which causes them to rely on their previous knowledge of risk and experience to form an opinion (Harrington et al., 2012b).

4.4.3 Management and Coping in Canada

Participants were asked to describe the changes they made to their lifestyle after being diagnosed with a food allergy (Table 4.7). While some participants were less stringent in avoiding foods (n=4), 83% of them took specific measures to avoid any contact with the allergen (n=15). Some of these measures occur within the home, such as reading food labels or buying

³ The hygiene hypothesis states that a lack of early childhood exposure to microorganisms, parasites, and infectious agents suppresses the development of the immune system, thereby increasing an individual's susceptibility to allergic disease.

alternative foods when grocery shopping. This mother explained the challenge of finding suitable alternatives for her daughter who has multiple allergies:

One thing is that every time we go buy food we have to read the ingredients. See to it that there is no milk or egg or peanut in it. So that is one thing and when preparing food for her, I have to use some substitute like egg substitute and milk substitute if I am going to bake cookies or cakes. Make something like has some milk or egg, I have to substitute those things. (Participant 5 - female from Philippines, <10 years in Canada, daughter is allergic to egg, milk, and peanut)

Overall, participants found that eating at home was not only more cost-effective, but also safer because they had control over their environment.

Table 4.7: Management strategies for food allergy

Strategy		Number of participants (% of the total)	Mentions (% of the total)
Avoidance	Sometimes	4 (22)	5 (3)
	Always	15 (83)	39 (20)
	Based on prior experience	11 (61)	23 (12)
Food Labels	No reliance	1 (6)	1 (1)
	Some reliance	4 (22)	6 (3)
	Heavy reliance	5 (28)	9 (5)
Changes within the Home	Grocery shopping	5 (28)	8 (4)
	Cooking	11 (61)	12 (6)
Changes outside the Home	Restaurants	17 (94)	35 (18)
	School	13 (72)	14 (7)
	Social gatherings	9 (50)	11 (6)
Medication	Epi-Pen	5 (28)	10 (5)
	Antihistamine (Benadryl)	3 (17)	6 (3)
	Alternative medicine	2 (11)	3 (2)
	Other	4 (22)	10 (5)
Total		18* (100)	192 (100)

* This is not equal to the sum of the numbers in the column due to multiple responses

Outside the home, participants would have to tell the staff at a restaurant about their allergy, bring their own food to social gatherings, and/or carry an Epi-Pen or Benadryl with them at all times.

If I eat in a restaurant, I would ask if they have certain ingredients that are involved with these foods. If not, I will, if it is, then I will try to avoid to order those dishes ... I have to bring my medicine as well if I eat something wrong, I can have some kind of protection.

(Participant 14 - female from China, <5 years in Canada, allergic to peanuts, beans, fish, and shrimp)

Although all the anaphylactic individuals in the sample carried an Epi-Pen (n=5), Benadryl was also mentioned by a few participants (n=3). Two participants also described their experience with using alternative medicine to treat their allergy while living in Asia:

My parents started helping me to treat my allergy back when I was fifteen or sixteen. I started eating this one particular thing called bird's nest. It is like a drink that is similar to ginseng. It is supposed to make your metabolism better. Every day I was drinking it. I wouldn't say for sure that I got better because of it.

(Participant 1 - female from Hong Kong, <10 years in Canada, allergic to lychee and lobster)

Many participants also shared scenarios where they used their previous experience with food to gauge whether or not something is safe to eat (n=11). Some participants who are allergic to shellfish choose to avoid seafood all together. Sushi restaurants, in particular, were perceived as an unsafe environment to participants with a fish or shellfish allergy. Participants tended to err on the side of caution if they were unsure about a food. Participant 11 even remarked that doing personal research before eating out was his preferred method for staying safe:

I do try and make sure that the restaurants that I go to I either order just like salads or foods that most likely don't have contact with seafood ... I scan the menu first, and if there is anything like that stands out, I will let them know, but as well a lot of my friends know of my allergies as well. So we do try to avoid places that are primarily seafood ... If it is a place I haven't heard before, I will try and Google it and see their menu, and see if it is like a place where you know they sell like other things besides seafood.

(Participant 11 - male from Thailand, <20 years in Canada, allergic to fish and shellfish)

Yes, generally blueberries are used in desserts, so I will just like watch out for pies. I will be like, "oh does it have blueberries." [For] the shellfish it is kind of obvious. They kind of use it in seafood, so I kind of stay away from most seafood conglomerate type foods, and I will just stick to basic fish.

(Participant 8 - male from Philippines, <20 years in Canada, allergic to blueberries and shellfish)

In addition, 72% of participants commented on their experience with having a food allergy while in school. The differences between schools in Canada and Asia are discussed in greater detail below; however, Participant 4 seemed to find social gatherings outside of home more worrisome than schools in Canada in terms of safety:

In school it is pretty good because now everybody is aware of allergies, so the biggest challenge would be like if he goes to another person's [house], like go to a birthday party, right? That kind of thing is more casual. The people may eat peanuts there, right on the cake. In school though, everybody is pretty much aware of that.
(Participant 4 - female from China, <10 years in Canada, son is allergic to peanut and beans)

Another participant described her sense of guilt when she could not eat seafood in social gatherings because it made her seem rude. While living in Hong Kong, she was not used to having people make accommodations for her allergy:

Sometimes I just feel bad for not having the food, because they make it with their effort and time. I just feel bad for not having it, and even if I [do have it], let's say they make me a soup or something, I can drink the soup, but I can't eat the shrimp or seafood that is inside, and that is always kind of rude to leave them out.
(Participant 9 - female from Hong Kong, <10 years in Canada, allergic to shellfish and selected fish)

Participant 9 is an example of someone who does not mind having seafood consumed around her, but prefers not to have it in her home. Approximately 61% of participants had similar comfort levels with food allergens as her. Only 3 participants said they felt completely uncomfortable with being exposed to a food allergen (Table 4.8).

Table 4.8: Comfort level with food allergen

Comfort Level	Number of participants (% of the total)	Mentions (% of the total)
Cannot be in household	3 (17)	4 (25)
Prefer not to have in household	4 (22)	4 (25)
Can be consumed in household	7 (39)	8 (50)
Total	14 (78)	16 (100)

* This is not equal to the sum of the numbers in the column due to multiple responses

Participant’s comfort level with the food allergen can have an impact on their general attitude towards having an allergy (Table 4.9). Only two participants felt that their allergy was not an inconvenience in any way. They saw their allergy as a more positive trait because it increased their awareness of the foods they consume. Both participants are also allergic to only one food, making it easier for them to find alternatives foods; in other words, neither participant felt terribly restricted by their allergy:

P: I think it is more trouble to eat out, [because] you have less choice. But, it is also a good opportunity for you to manage your food allergy, to take care of yourself. [You learn to] pay attention to what you are eating; I think that is the bright side of having an allergy.

(Participant 13 - *female from China, <5 years in Canada, allergic to mango*)

Table 4.9: General attitude towards food allergy

Attitude	Number of participants (% of the total)	Mentions (% of the total)
Positive	2 (11)	3 (16)
Negative	8 (44)	8 (42)
Neutral	7 (39)	8 (42)
Total	17 (94)	19 (100)

For those who saw their allergy as an inconvenience, their general attitude was either neutral or negative (n=15). Approximately 39% of participants stated that they are used to having an allergy and that it was not an inconvenience to them. For those who had a negative attitude, it was usually because they used to like the food they are allergic to:

Yea, it was pretty frustrating, because I love fish, and then my mom told me you can’t eat fish any more, and really, I had a huge craving for fish for a long time.

(Participant 14 - *female from China, <5 years in Canada, allergic to peanut, beans, fish, and shrimp*)

Negative feelings towards their allergy also seemed to stem from the lack of support they felt in their social circles. Participants 1 and 3 did not appreciate being called “picky” because of their allergy:

So in terms of lifestyle it did affect my lifestyle right because you see other people eating it, you can't eat it, or you have to be very picky with your food, so I think growing up I was known to be like I have to be picky, not like because I want to, because like you just have to be.

(Participant 1 - female from Hong Kong, <10 years in Canada, allergic to lychee and lobster)

Just like my mom, like she is always like she is not allergic to anything, so she is always like "why are you allergic?" Yea it is funny there is a phrase that she says. It is like my sister she always say my sister like if she cooks anything that, my sister will eat anything that my mom cooks, but I am always the weird kid that I always have to be careful with, that it always has so many limitations to the food that I eat, right? So it is just kind of annoying at times.

(Participant 3 - male raised in Hong Kong, <20 years in Canada, allergic to shellfish and peanut)

As explained in Section 2.5, a food allergy impacts the quality of life of not only the allergic individual, but also that of their family. The presence of a strong support system can make a positive difference in helping an allergic individual cope. Coping was explored by gauging the level of support allergic individuals received from their family and friends (Table 4.10).

Table 4.10: Family and friend's attitudes towards food allergy

Attitude	Family		Friends	
	Number of participants (% of the total)	Mentions (% of the total)	Number of participants (% of the total)	Mentions (% of the total)
Surprise	4 (22)	7 (14)	1 (22)	1 (3)
Skeptical	7 (39)	8 (16)	3 (17)	4 (13)
Scared	2 (11)	2 (4)	0	0
Quick acceptance	4 (22)	4 (8)	3 (17)	3 (10)
Slow acceptance	5 (28)	8 (16)	2 (11)	2 (6)
Disappointment	0	0	1 (6)	1 (3)
Supportive/Cautious	13 (72)	19 (39)	13 (72)	20 (65)
Other	1 (6)	1 (2)	0	0
Total	18* (100)	49 (100)	18* (100)	31 (100)

* This is not equal to the sum of the numbers in the column due to multiple responses

Fortunately, 72% of participants said that their family and friends are supportive because they understand the severity of the issue and they are willing to make accommodations for the

allergic individual to help them avoid an allergic reaction. Participant 15 appreciated the support she received from friends because they took an active role in making sure she did not eat anything harmful by accident:

A lot of friends typically know, so if I am not sure [if I should be eating something], they will taste the food first, and be like “okay, I think this contains peanut, so I don’t think you should have this,” or “I think this contains shellfish, so you definitely shouldn’t have this.” (Participant 15 – *female raised in Singapore and Japan, <5 years in Canada, allergic to peanut and shellfish*)

Interestingly, some participants made distinctions between the different generations in their family in terms of support. Grandparents were seen as less supportive members of the family because they are less aware of the consequences of being accidentally exposed to an allergen.

I would say my immediate family was more cautious of it. Whenever we would have shrimp, they would make at least a few dishes that were non-seafood ... I would say my family took it quite well. My grandmother was the one that didn’t quite understand that I was allergic to shrimp. (Participant 16 – *female from Malaysia, <5 years in Canada, allergic to shrimp*)

A similar observation about grandparents has been made in a study that was not ethnically-focused. Mandell et al. (2005) found that the parents of allergic children perceived a lack of cooperation from the grandparents, with respect to allergy management, causing tensions within a family. Moreover, grandparents are more likely to rate the risk of food allergy as high, when compared to younger individuals (Harrington et al., 2012b). These findings suggest that grandparents and/or older adults are less familiar with food allergies than the general population, possibly due to the fact that food allergies are a relatively new public health concern.

A surprising 39% of participants reported that their family was initially skeptical of their food allergy. Family members, particularly the parents, were sometimes slow to accept that food allergies are a real medical condition:

During my first visit to the doctor, nobody believed I am allergic to any like, to a kind of tropical fruit. Even the second time I was diagnosed to be allergic to mango, [my family], they like didn't believe it. But three years later, I will still get a rash on my face [when I eat mango]. It is because I accidentally ate a piece of mango that they then totally believed I am allergic. After that they became supportive.

(Participant 13 - *female from China, <5 years in Canada, allergic to mango*)

A lot of people are skeptical. My relatives [will say something] like "are you sure that you are allergic to it?" "Maybe you should try without knowing it and see if it is a psychological thing." But I actually proved it to them many times that I am allergic. It is actually about my physical reaction. (Participant 3 - *male raised in Hong Kong, <20 years in Canada, allergic to shellfish and peanut*)

Participants had to "prove" their allergy to their relatives by showing them the physical reaction they would have if they consumed an allergen. Once relatives were able to accept the condition, they would have a supportive attitude.

Misinformed perceptions about oral immunotherapy were also raised, as participants had experienced situations in which they were encouraged by family members to eat an allergen. The thinking was that regular exposure to the allergen would eventually cure them of their condition:

[My dad] is like just keep eating, because whenever there were shrimps or like at home, my dad would always kind of force me to eat it, and he would be just like oh it is all in your head. You can like overcome it if you just slowly like try to build immunity against it ... But I kind of didn't want to do it, just because I was afraid of getting a reaction.

(Participant 7 - *male from Philippines, <20 years in Canada, allergic to shrimp and shellfish*)

4.4.4 *Management and Coping in East and Southeast Asia*

To capture political and cultural differences between Canada and Asia, participants were asked a number of questions about their allergic experience in both places. In general, participants found it harder to manage their allergy in their birth place because of lower levels of

awareness. This section of results does not reflect the views of all 18 participants since some of them did not develop a food allergy until they moved to Canada.

Table 4.11 suggests that the majority of participants found it more difficult to cope with their allergy while living in Asia (n=8). None of the participants reported that it was easier.

Table 4.11: Level of difficulty when coping with food allergy in birth place

Level of Difficulty	Number of participants (% of the total)	Mentions (% of the total)
Easier	-	-
Same	2 (11)	2 (14)
Harder	8 (44)	12 (86)
Total	10 (55)	14 (100)

Participants attributed this difference to lower levels of awareness, and subsequently, less respect and understanding of their needs for accommodation.

Yes, it is definitely a different level of awareness for different foods, much more [in Canada] than in Malaysia. I think people are more respectful too. There is more awareness, so people kind of respond to [my allergy] in a positive light and they are really considerate about it, allowing me to have different eating, yea different eating conditions.
(Participant 16 - *female from Malaysia, <5 years in Canada, allergic to shrimp*)

More specifically, 39% of participants stated that lack of accommodation (in restaurants and in schools) of their allergy was an obstacle to management in their birth place. Other identified obstacles are shown in Table 4.12.

Table 4.12: Obstacles to managing food allergy in birth place

Obstacle	Number of participants (% of the total)	Mentions (% of the total)
Different eating habits	3 (17)	4 (18)
Different attitudes towards food	2 (11)	2 (9)
Less accommodative (in restaurants, schools, etc.)	7 (39)	9 (41)
Different health safety standards	5 (28)	6 (27)
Cost	1 (5)	1 (5)
Total	18 (100)	22 (100)

“Different eating habits” refers to methods of cooking or food availability that make it challenging for an allergic individual to know what their food contains. In one instance, a participant from Malaysia found that shrimp is easier to avoid in Canada:

Yes it is much easier to avoid shrimp [in Canada] because the foods aren't mixed. The sauces are simpler and you can see the food individually versus Malaysian cuisine where everything is mixed together and you don't know what went into the dish.

(Participant 16 - *female from Malaysia, <5 years in Canada, allergic to shrimp*)

Similarly, a participant from Hong Kong found a difference in attitude towards food preparation and service in Asia. Available food and menus in restaurants change often in Hong Kong because they want to keep the customer's interest. The result is more innovative dishes that, again, make it challenging for allergic individuals to know what ingredients are used in their foods:

In Hong Kong, people mix food. They tend to create more different ways to make food than here [in Canada]. Food in Canada is more generic. People always have the same way of making a particular dish, but in Hong Kong, I guess because it is a tourist city, people want to be creative. They want to attract more customers, so they have a lot more innovative dishes.

(Participant 1 - *female from Hong Kong, <10 years in Canada, allergic to lychee and lobster*)

Individuals with a food allergy feel safer going to restaurants they are familiar with because the offerings and health safety standards are consistent. Participant 3 was very impressed with the level of service he received at a Canadian restaurant because they took his allergy seriously:

In China, nobody really cares [about your allergy] whereas here [in Canada] they do ... One time I went to [popular chain restaurant]⁴ and their service is absolutely superb. I told them I am allergic to seafood, just to make sure there's nothing in my food and then the manager came by. He just wanted to stop and say hi and say that they are very careful and that there will absolutely be no seafood in my meal. I was really impressed that they took an extra step to make sure my food is proper.

⁴ Company names have been removed from participant interview transcripts.

(Participant 3 - male raised in Hong Kong, <20 years in Canada, allergic to shellfish and peanut)

Another obstacle to managing a food allergy in Asia, which was unexpected, is cost.

Participant 10 explained that seeing a private doctor in the Philippines is not affordable to everyone. Receiving confirmation of a food allergy is a lesser priority when that money could be spent on daily necessities:

The amount of money that it would cost people to go to a private doctor would eat into their daily [expenses], you know, their daily consumption of food, etc. Instead of actually seeking help and going to a private practitioner to get tested [for an allergy] and all of these things, [people in the Philippines] would rather not. They rather eat, pay for their bills, etc.

(Participant 10 - female from Philippines, <5 years in Canada, allergic to shellfish)

Simply put, this participant does not believe that food allergies are seen as a health priority.

While food allergies may be a nuisance to some, it is not a health issue that is commonly spoken about. Therefore, it is unsurprising that most participants stated that the level of awareness of food allergies in their birth place is low compared to Canada. As discussed in Section 2.2.3, reported prevalence of food allergy is lower in Asia than it is in North America.

In addition, 67% of participants stated that there is a low level of awareness of food allergies due to differences in education, health priorities, and more (see Table 4.13). “Perceived prevalence” of food allergies, as previously mentioned, is lower in Asia, making it the most plausible explanation to participants (n=4).

Table 4.13: Explanation for perceptions on food allergy in birth place

Explanation	Number of participants (% of the total)	Mentions (% of the total)
Education	3 (17)	3 (16)
Perceived prevalence	4 (22)	6 (32)
Health priorities	3 (17)	4 (21)
Diagnostic testing	3 (17)	5 (26)
Other	1 (6)	1 (5)
Total	14 (79)	19 (100)

However, participants also referred to lack of “Education” and opportunities for “Diagnostic testing” as reasons for a low level of awareness of food allergies. Interestingly, 3 participants stated that an allergic person in Asia may acknowledge the fact that their body reacts negatively when they eat specific foods; however, they may be unaware that their reaction is a response of the immune system and not something else:

I guess I am fortunate in that I have the education and the background. Allergies are everyday stuff to me. [For others], these reactions, they recognize it, and know to take antihistamines or head to the hospital if something really goes wrong, etc., but a lot of people back home of a [lower social] class, they are probably not aware of it. For example, we had [hired household] helpers and you could see that they were reacting to certain food. You could tell them, “you know what you have is an allergy to what you are eating,” but they won’t know what you are talking about. They just say “every time I eat crab this happens and that happens.” Well, that is an allergy and you can actually do something about it, but they are not aware of it.

(Participant 10 - female from Philippines, <5 years in Canada, allergic to shellfish)

Participant 10’s observation about her household staff in the Philippines is one reason why she perceives a low level of awareness of food allergies.

In addition to personal experiences, participants were asked to identify other social differences in their environment that led them to conclude that there is a higher level of awareness of food allergies in Canada. These social influences (or indicators of awareness) are listed in Table 4.14. In this table, “Education” refers to differences participants noticed when they came to school in Canada such as the implications of Sabrina’s Law (e.g., peanut-free zones). Participant 8 made reference to both “Education” and “Food labelling” as indicators of a high level of awareness in Canada:

No I like peanuts and in the Philippines they don’t have like peanut free zones kind of thing. In fact they sell them at schools, but here they have to have signs. They even have like specific products that have a clear label on them – “No peanuts.”

(Participant 8 - male from Philippines, <20 years in Canada, allergic to blueberries and shellfish)

Another participant noticed the level of emphasis that is placed on food allergies in the Canadian school system:

Over here like there is a lot of emphasis, like one of the first things you learn in school is to don't bring any peanut food and stuff. You don't find that in China.

(Participant 12 - female from China, <20 years in Canada, allergic to shrimp and prawns)

Participants were also asked if they are aware of any existing policies in their birth place that was related to food allergies. Few of them were able to comment about policies but those who did were not aware of any (n=5).

Table 4.14: Indicators of level of awareness of food allergy in birth place

Indicator	Number of participants (% of the total)	Mentions (% of the total)
Education	6 (33)	6 (10)
Food labelling	6 (33)	11 (17)
Health promotion	1 (6)	1 (2)
Media	3 (17)	4 (6)
Restaurants	4(22)	4 (6)
Terminology	11 (61)	20 (32)
Policies	Not aware of any	5 (28)
	Aware of some	1 (6)
“Food allergy” in other languages	Chinese	5 (28)
	Malay	1 (6)
	Thai	1 (6)
	Japanese	1 (6)
Total	18* (100)	63 (100)

* This is not equal to the sum of the numbers in the column due to multiple responses

The most notable finding regarding awareness of food allergies in Asia came from discussions about food allergy terminology. Participants were asked to describe their familiarity with the term “food allergy” before they moved to Canada. If they had lived in Asia with a food allergy prior to immigrating, they were also asked how to say “food allergy” in their native

language. The indicator “Terminology” in Table 4.14 shows that 61% of participants spoke on this topic in their interview.

Not all participants were asked about how food allergies are spoken about in their native language since it was a theme that emerged half way through the interview process. The gathered responses vary widely. For some participants, they had no prior knowledge of what a food allergy was, even if they had one, until they came to Canada:

R⁵: When you were growing up were you familiar with what food allergies are?

P: No, I actually wasn't. I didn't even know anyone who had allergies. It was only when I came to Canada that I had heard that people have allergies to peanuts and stuff like that. I didn't know how severe it can get, that people can actually get it, etc.

(Participant 11 – *male from Thailand, <20 years in Canada, allergic to fish and shellfish*)

It was only after they came to Canada that they became familiar with the terminology. For three participants who moved to Canada within the last ten years, however, their familiarity with terms such as food allergy, anaphylaxis, and food intolerance is even less:

R: What about anaphylaxis? Do you know what that means?

P: No, I have no idea.

(Participant 13 – *female from China, <5 years in Canada, allergic to mango*)

Moreover, when interviewing Participant 2, a female who has lived in Canada for less than 5 years, she asked what the difference is between food allergy and food intolerance. She was also unfamiliar with anaphylaxis and Epi-Pens. Another common misconception amongst a few participants was that lactose intolerance was a type of food allergy:

R: So who in your family has a food allergy?

P: I do. My mom is lactose intolerant. And I think that is it.

(Participant 17 – *female from China, <20 years in Canada, allergic to shellfish*)

⁵ R refers to the question asked by the researcher. P refers to the participant's response.

This finding is not unlike population-based studies in North America that have estimated the prevalence of food allergy using self-reported measures. The studies tend to overestimate the prevalence of food allergy because individuals have a tendency to identify any discomfort from food as a food allergy (Harrington et al., 2012b).

Furthermore, when participants were asked to recall the equivalent of “food allergy” in their native language, there were no official terms they could use to describe differences in severity. For example, 28% of participants could say “food allergy” in Chinese (Mandarin and Cantonese), but there was no equivalent term in Chinese for “anaphylaxis.” The same observation was made by participants who spoke Malay, Thai, and Japanese.

R: Is there any difference in the way that people speak about food allergies? Here we have terms like food allergy, food intolerance, and anaphylaxis.

P: I think it was a really broad term [in Malaysia] which was one word that would be “allergy.” I found that it wasn’t specific enough, and like it’s really rare to hear someone use the word anaphylaxis or intolerance.
(Participant 16 – *female from Malaysia, <5 years in Canada, allergic to shrimp*)

P: I went to a local school in Japan, so I am pretty much fluent.

R: Do they have a specific word for food allergy?

P: No, they don’t actually. There is no word for it.

R: Okay, so how would you have to describe a food allergy then in Japanese?

P: You basically have to, because there is no word, you just tell them in a sense that you can’t tolerate this food because your system can’t take it, like your body can’t take it. They usually get it by then ... They know the concept, I just don’t think they have a word.

(Participant 15 – *female raised in Singapore and Japan, <5 years in Canada, allergic to peanut and shellfish*)

It was speculated by some participants that familiarity with food allergies in Asia may increase over time, but at this point it has not been recognized as a medical condition, at least not in the general population. This is reflected by the lack of policies related to food allergies and the language used in people’s everyday conversations.

In summary, participants found that managing a food allergy is more difficult in Asia because of the lack of awareness, and consequently, the lack of accommodation that has been put in place in restaurants and schools that are commonplace in Canada. Although medical professionals may be aware of distinctions in severity of food allergies, the general population is not. It is possible that individuals who have a food allergy simply do not have the knowledge to identify their condition as such.

4.4.5 *Quality of Life*

In addition to external differences in Canada and Asia that are related to food allergies, participants were also asked to describe their overall perception of health in a more personal sense. Even though every participant is directly affected by food allergies, its impact on quality of life varies in each individual. Table 4.15 attempts to capture the participant’s overall sense of quality of life by organizing it into three categories: lifestyle, environment (social and physical aspects), and diet.

Table 4.15: Quality of life in Canada vs. birth place

		Number of participants (% of the total)	Mentions (% of the total)
Similarities with Birth Place	Canadian Lifestyle	1 (6)	1 (1)
	Canadian Environment ⁶	1 (6)	1 (1)
	Canadian Diet	1 (6)	1 (1)
Differences with Birth Place	Canadian Lifestyle	2 (11)	3 (3)
	Canadian Environment ⁶	12 (67)	28 (30)
	Canadian Diet	10 (56)	19 (20)
Improved Characteristics	Canadian Lifestyle	3 (17)	4 (4)
	Canadian Environment ⁶	13 (72)	21 (22)
	Canadian Diet	2 (11)	2 (2)
Worsened Characteristics	Canadian Lifestyle	2 (11)	3 (3)
	Canadian Environment ⁶	3 (17)	3 (3)
	Canadian Diet	5 (28)	8 (9)
Total		18* (100)	94 (100)

* This is not equal to the sum of the numbers in the column due to multiple responses

⁶ Environment includes both social and physical aspects of the participant’s surroundings.

With respect to physical and social environment, 72% of participants agreed that their quality of life improved upon moving to Canada. For physical environment, participants commented on the benefits of fresher air. Air pollution is severe in heavily urbanized regions of Asia and its effect on health was felt by two participants:

In Canada it is a lot less crowded. The air is fresher. The life pace is slower. Yea, and the traffic isn't as bad ... I think I feel much healthier in Canada, because every time I travel back to China to visit my grandparents, I got a terrible cough. Like, the air is so bad.
(Participant 14 - *female from China, <5 years in Canada, allergic to peanut, beans, fish, and shrimp*)

So for example, air pollution. In Hong Kong I had different kinds of allergies, like nasal allergy, and it was pretty severe when I was in Hong Kong because of the air conditioning. When I arrived in Canada, after two or three years here, I stopped having those allergies. I just sneeze a lot less.
(Participant 1 - *female from Hong Kong, <10 years in Canada, allergic to lychee and lobster*)

From a social standpoint, participants described Canada's society as "civilized," "friendly," and "understanding". In terms of lifestyle changes, a few participants commented on having a slower pace of life in Canada. For the most part however, the changes were small.

Not surprisingly, changes in diet seemed to have the biggest influence in the everyday lives of the allergic individuals, as 56% of participants mentioned it in their interview. Participants spoke about Canada's heavy reliance on processed foods and the limited availability of fresh foods compared to what they were used to in Asia. Approximately, one third of participants felt that their diet had worsened since moving to Canada.

Here in Canada foods are a lot more processed and industrial ... But in the Philippines, it is very much a farming country, and you literally get your vegetables from your next door neighbour, and then you just cook it yourself. The food doesn't go through a middle man, or agricultural conglomerate company that kind of does whatever to it.
(Participant 8 - *male from Philippines, <20 years in Canada, allergic to blueberries and shellfish*)

Table 4.16 shows that there may be a trade-off for freshness and safety standards in food. Approximately 61% of participants thought that foods in Canada are safer to eat than in Asia, despite being more processed.

Table 4.16: Accessibility and consumption of traditional foods in Canada

	Number of participants (% of the total)	Mentions (% of the total)
Characteristics of Food Eaten in Birth Place	11 (61)	28 (49)
Consumption of Traditional Foods in Canada	4 (22)	5 (9)
Accessibility of Traditional Foods in Canada	3 (17)	4 (7)
Level of Safety Compared to Western Cuisine	11 (61)	16 (28)
Level of Preference Compared to Western Cuisine	4 (22)	4 (7)
Total	18* (100)	57 (100)

* This is not equal to the sum of the numbers in the column due to multiple responses

Two participants who have worked in food services in Canada also commented that safety standards are high. Both individuals felt that the level of safety training they received in Canada was taken very seriously whereas safety training is not always enforced in food services in Asia.

P: The place I am working at is a food service, so when I am working I will be more cautious about food allergy ... If the person tells me that he or she is allergic to some sort of food, I will clean the blender thoroughly before making the drink.

R: If you were back in Hong Kong with a similar job, do you think that there would be a difference?

P: Yes, because one summer I was in Hong Kong, I worked at a restaurant as a waitress and I wasn't that careful. The person with an allergy would be more cautious about the food he or she is consuming, but the worker, I don't think they take it seriously.

(Participant 9 - female from Hong Kong, <10 years in Canada, allergic to shellfish and selected fish)

Participant 9 acknowledged the fact that when managing a food allergy in Asia, the onus is on the individual to know what is and what is not safe to consume. For some participants, they did

not mind the change in their diet since coming to Canada because it is simply easier for them to avoid certain foods. There are also fewer additives in Canadian foods such as MSG (monosodium glutamate) which was brought up by two participants as a drawback to Asian cuisine.

To help summarize the overall impact of allergy on quality of life in this group, transcripts were interpreted and organized around three levels of impact (Table 4.17). A participant’s experience was categorized under “negligible” if they adapted quickly to their food allergy and never felt any serious disappointment from being allergic. The 39% of participants under this category rarely liked the food they are allergic to in the first place. The majority of participants (61% of them) felt that their allergy had a “noticeable” impact on their quality of life as it took them some time to accept their allergy and learn how to manage it. The allergy often went from being a nuisance to just a fact of life for them. For the 3 participants who have been heavily impacted by their allergy, 2 of them have multiple allergies. Their allergy is perceived to be a major inconvenience as they have to be extremely cautious about what they eat. Each of these participants expressed a different frustration with their allergy. One had tried multiple remedies, both Chinese and Western medicine, to stop her rashes. Another participant had been teased by family and friends about his food allergy.

Table 4.17: Impact of food allergy on quality of life in Canada

Impact Level	Number of participants (% of the total)	Mentions (% of the total)
Negligible	7 (39)	18 (46)
Noticeable	11 (61)	14 (36)
Significant	3 (17)	7 (18)
Total	18* (100)	39 (100)

* This is not equal to the sum of the numbers in the column due to multiple responses

Participants were also asked for their thoughts with regards to how their quality of life, or those of other immigrants, may be improved with respect to food allergies (n=6). One participant thought that it would be useful to create brochures that are specific to new Canadians:

I think little brochures that can easily be handed out to people, saying what major allergic foods are in Canada, and [what to do] if your child has certain reactions would be useful.
 (Participant 14 – female from China, <5 years in Canada, allergic to peanut, beans, fish, and shrimp)

Several participants also expressed an interest in having resources on food allergies that were in other languages besides English.

The last set of questions that were asked during the participant interviews were about sources of allergy information based on their helpfulness and trustworthiness (Table 4.18).

Approximately 56% of participants said that their physician was their go-to source for information. Three of the four mothers with an allergic child who participated in the interviews, identified their allergist as being extremely helpful. Community and public health services were mentioned less than physicians and allergists, with 14% of total mentions.

Table 4.18: Sources of food allergy information

Source	Number of participants (% of the total)	Mentions (% of the total)
Physician	10 (56)	19 (53)
Allergist	4 (22)	12 (33)
Community or Public Health Services	4 (22)	5 (14)
Total	18 (100)	36 (100)

Table 4.19 also shows that personal research done on the Internet was the preferred method for learning more about food allergies. Approximately 67% of participants said that they have conducted an Internet search on food allergies, at least once. Participants have used the Internet to check food menus, read sites like Mayo Clinic, or find strategies for management. The level of curiosity about food allergies differed greatly amongst participants. While 22% of

them never felt the need to do research, some participants, like this mother, had used the Internet extensively to see if she could find out why her son has an allergy:

R: Have you ever tried to find more resources to learn about how to help him cope? What are some of the things that you have done?

P: Yea, thank god we have Internet. A lot of information is on the Internet. We have spent lots of time doing that ... I can't remember the website I went to, but I do a lot of research. I try to dig into why he has this allergy. I have spent tons of time trying to figure that out. Unfortunately, I haven't found out why.

(Participant 4 - female from China, <10 years in Canada, son is allergic to peanuts and beans)

Table 4.19: Personal research on food allergy

Personal Research	Number of participants (% of the total)	Mentions (% of the total)
Yes	12 (67)	16 (80)
No	4 (22)	4 (20)
Total	16 (89)	20 (100)

Finally, Table 4.20 is a report of the type of information the participants received from a physician or allergist when they were diagnosed with an allergy. This question only applied to those who received a proper diagnosis as there were several participants who self-diagnosed their allergy. A surprising 33% of participants did not receive any resources such as an instructional sheet or pamphlet about food allergies. Moreover, 2 participants were unsure if they had received anything.

Table 4.20: Food allergy information given upon diagnosis

Information Type	Number of participants (% of the total)	Mentions (% of the total)
None Given	6 (33)	6 (50)
Pamphlet/Brochure	1 (6)	2 (17)
Handout or Fact Sheet	2 (11)	2 (17)
Other (or Unsure)	2 (11)	2 (17)
Total	11 (61)	12 (100)

The manner in which allergic individuals receive their information about food allergies is important to know since proper management is a necessary and life-long skill.

4.5 Chapter Summary

From the documentary analysis and key informant interviews, it was confirmed that there are currently no resources on food allergies that have been tailored to new Canadians. Although food allergies are not a primary health concern for immigrants, those who are affected are often surprised or skeptical of the seriousness of anaphylaxis. The key informant interviews demonstrated that there is still room for improvement in terms of raising awareness. As with any health issue, unfamiliarity can breed misconception. Therefore, medical and public health communities have a responsibility to ensure that the information that is being disseminated to the general public is both accurate and easily accessible.

The in-depth interviews with 18 participants provide insight into understanding how new Canadians manage and cope with their food allergy. With respect to perceived prevalence and risk, most participants believed that the prevalence of food allergies in Canada is higher than it is in Asia. They pointed to differences in diet, environment, and education to explain this trend. Another reoccurring theme was that participants felt surprised and skeptical of their food allergy when they had their first allergic reaction or diagnosis. Their ability to adopt strategies to avoid foods was also heavily influenced by their support system of family and friends. Moreover, participants who had lived with an allergy in Asia before immigrating to Canada found that the environment in Canada is very accommodating. Food labelling, school policies, and social acceptability of having a food allergy lessened its impact on their quality of life. In addition, food allergies are a part of the everyday language in Canada, a contrast to most places in Asia. Differences in language use and terminology emphasize the importance of health literacy and the need for improved awareness of food allergies among the immigrant population.

The social and policy implications of this research will be discussed in the following chapter. The key findings of this thesis will also be reported in the context of published research. Chapter 5 will also cover the contributions and limitations of this thesis in order to encourage further research on this topic.

CHAPTER FIVE

Discussion and Conclusions

5.1 Introduction

Increased prevalence and awareness of food allergy has become a global phenomenon, making it a major public health concern. However, because little is known about the etiology of food allergies, it is a disease that is easily misunderstood by the general public. More specifically, all Canadians, including recent immigrants, perceive the risk of food allergy to be greater than systematic estimates (Harrington et al., 2012a). Without understanding the public's perception of risk, and how these opinions are formed, policy regarding food allergy may be misinformed and ineffective (Slovic, 1987). Therefore, this thesis has sought to examine the gap in perceived and actual risk of food allergy from the perspective of new Canadians. Three objectives have guided this research:

- 1) To explore the policy context around food allergy for new Canadians
- 2) To understand how a specific ethnocultural group perceives food allergies and its associated risks
- 3) To appreciate how new Canadians manage and cope with food allergies

In this final chapter, key findings are explained, compared, and contrasted with the literature.

The contributions, policy implications, and limitations of this thesis are also discussed. Finally, suggestions are made for further research.

5.2 Key Findings

The documentary analysis of policy and/or resource documents was an efficient method to gauge the current policy context around food allergies for new Canadians. No online resources tailored to new Canadians were identified (Section 4.2.1). This finding was not surprising and

was re-confirmed by key informants. It supports the hypothesis that immigrants have a lower level of awareness about food allergies, hence, their inflated perception of risk. This finding also indicates that new Canadians should be considered a unique audience in efforts to increase awareness about food allergies. In addition, it is important that immigrants have access to reliable information that can easily be found on the Internet. Findings suggest that there is a wide variation in quality of information that is distributed to patients when they are diagnosed, if they receive any at all (Table 4.20). Consequently, new Canadians use the Internet as their preferred method for doing personal research about their allergy (Table 4.19). The key informants interviewed also rely on Internet sources for their own reference and as a resource to pass on to affected individuals (e.g., allergic patients, parents with allergic children, teachers and principals, etc.). Hence, health professionals and leaders in food allergy advocacy should be encouraged to tailor comprehensive, online resources that are available and accessible to new Canadians.

Key informants also expressed concern for allergic children and how they are perceived by their peers. Issues of food allergies in schools often appear in Canadian media, having a powerful influence on the public's perception of food allergies as well as their response to school policies and practices. This is consistent with Harrington et al. (2012a) who found that a high proportion of parents of allergic children were quoted in media representations of the food allergy issue. More often than not, this has led to feelings of exclusion for allergic children, impacting their quality of life (Fenton et al., 2011). The participants who had lived with their food allergy in Asia also expressed similar feelings of exclusion and frustration as they were used to fending for themselves, especially if they were the only one in their social circle with a food allergy (Table 4.10). In this respect, the anxieties and concerns of allergic children in the Canadian school system are very similar to individuals who have grown up in Asia with an

allergy. It is even arguable that the participants who grew up in Asia had a more difficult time adapting to and managing their allergy than Canadian-born allergic individuals because their policy environment was far less accommodating (Table 4.7, 4.11, 4.12). Participants shared many instances where there was a lack of accommodation for their allergy in public settings in Asia such as schools and restaurants.

With respect to the background of the interviewed participants, there were a few noticeable differences about the nature of their food allergies. Studies suggest that such differences are the result of very complex gene-environment interactions which play a role in the pathogenesis of allergic diseases. For example, shellfish was the most common allergen amongst participants. This finding agrees with studies from Asia where shellfish allergy predominates. In contrast, the risk of peanut and tree nut allergy is much higher in individuals from Western countries (Ben-Shoshan et al., 2012a; Goh et al., 1999; Hajeb & Selamat, 2012; Shek et al., 2010). While the influence of place of birth in development of shellfish allergy is still unknown, it is likely that multiple environmental factors are contributing to this phenomenon, including gender, living environment (urban vs. rural), and age of intake (Ben-Shoshan et al., 2012a). Researchers are only beginning to find potential links between age of fish intake and allergic disease (Kiefte-de Jong et al., 2012; Oien et al., 2010) which may also be the case of shellfish allergy. These links are further complicated by genetic predisposition (Shek et al., 2010).

The second interesting characteristic about the participants is that the average age of allergy diagnosis was 10 years old (Table 3.1). This characteristic is a sharp contrast to the high rates of allergic children in North America who are diagnosed at a much younger age (between 2 and 4 years) (Gupta et al., 2011). While reasons for this trend are unclear, contributing factors may include a lower level of awareness in immigrant groups and limited availability of

epinephrine auto-injectors in Asia. Findings of this thesis suggest that epinephrine auto-injectors are not widely used in Asia, as participants were unfamiliar with its use, despite having a food allergy (Table 4.7). This finding is supported by studies in Asia that show a low frequency of prescription of Epi-Pens (Shek et al., 2010; Tham et al., 2008). In countries such as the Philippines, Epi-Pens are not even available due to cost constraints (Shek et al., 2010). Limited accessibility to health care in parts of Asia is another related factor which may partially explain why several participants never opted to have their food allergy confirmed by a doctor.

Findings on perceived prevalence of food allergies and risk perception were as expected. The majority of participants perceived food allergies as a bigger health concern in Canada than in Asia. Participants cited food labelling practices and school board policies as proof since they were unaware of any similar legislation in Asia (Gerez et al., 2010). They also attributed differences in prevalence to the Canadian diet and genetics. Many of the participants commented on the high amount of processed foods that are commonly consumed in Canada (Table 4.15). It was also speculated that the use of pesticides and antibiotics in foods may be a contributor to the higher rates of food allergies in North America, an unexpected finding. Furthermore, fewer participants viewed the environment as a factor for susceptibility to allergic disease than expected. The hygiene hypothesis, a predominant perception about food allergies in the general public, was only mentioned by three participants (Table 4.6). That said, participants did mention their appreciation for the cleaner air in Canada which helped alleviate respiratory problems they suffered from while living in Asia.

In terms of management and coping, participants relied on food labels and prior experience with allergens to stay safe (Table 4.7). This finding is not unlike allergic individuals in the Canadian population, who have been shown to use prior experience as a determinant for

purchasing a product, especially since precautionary statements remain a voluntary risk management tool (Chow, 2011). However, discussions about the use of alternative medicine and oral immunotherapy appeared to be a specific to new Canadians. For example, two participants had been given alternative medicine in Asia to alleviate their allergic symptoms. Studies have shown that alternative medicine may be an effective treatment for asthma (Li & Brown, 2009), but the evidence remains insufficient to recommend it (Chapman & McIvor, 2009). Even less is known about alternative medicine and food allergies. Both participants who tried it as a therapy did not find it effective. Another issue that was raised during the participant interviews was unsupervised oral immunotherapy. Although participants were not familiar with the term “oral immunotherapy,” a number of them described their family and friends as having the perception that eating an allergen in small doses would cure them of their allergy. This misconception is concerning as oral immunotherapy is still in its infancy and has not been recommended as a treatment for food allergies (Ben-Shoshan & Clarke, 2011; Chaudhry & Oppenheimer, 2012). Moreover, this practice put participants in an uncomfortable situation, which could have possibly lead to accidental exposure and/or issues of management anxiety.

In summary, the findings of this thesis provide a partial explanation for the inflated perception of risk of food allergies held by new Canadians. There is a stark contrast between Canada and Asia in terms of the policy and social contexts for food allergies. This thesis also demonstrates that public perceptions of health are easily fed by misinformation and/or lack of information and awareness. Health professionals and public health leaders should be encouraged to disseminate accurate and timely information about food allergies to all Canadians, including new Canadians. This is of utmost importance as many unanswered questions remain about food allergies, its prevalence, and etiology.

5.3 Contributions

This thesis makes several substantive, theoretical, and methodological contributions to the existing literature on food allergies. First and foremost, it is the only research to have focused on Canadian immigrants from East and Southeast Asia and their experiences and perceptions of food allergy. Canadian immigrants are a unique sub-population often overlooked in health research because they are generally more difficult to recruit (Rooney et al., 2011). Strategic recruitment is a challenge for epidemiologists working to estimate the prevalence of food allergies and identify its demographic predictors. This thesis demonstrates that Canadian immigrants face unique challenges and concerns when it comes to managing their food allergy, thereby confirming the importance of their inclusion in relevant studies. In addition, this thesis suggests that studies on Canadian immigrants may provide new insights to understanding the etiology of food allergies, given the immigrants' birth place and long-term exposure to a different lifestyle, social and physical environment, and diet.

Furthermore, this thesis provides an in-depth understanding of a small group of individuals, following the social constructionist approach. The same theoretical approach has been used to improve understanding of recent immigrants (Asanin Dean & Wilson, 2010; Elliott & Gillie, 1998) and also allergic individuals (Akeson et al., 2007; Avery et al., 2003; Fenton et al., 2011; Hu et al., 2005; Mandell et al., 2005; Sampson et al., 2006), but not individuals belonging to both categories. Moreover, qualitative methods lend themselves well to the social constructionist approach. While the results of this thesis are not meant to be generalized to all immigrants with a food allergy, it is an accurate account of the participants that should resonate with others of a similar background.

To do this, methodological rigour was established by using a triangulation approach. This thesis is an example of how three data collection methods can be used to answer one research question with the purpose of ensuring completeness and confirmation. For example, confirmation was achieved when both a key informant and several participants described skepticism as a common attitude/reaction to food allergies in newer immigrants. Because this observation was consistent across multiple methods, the trustworthiness of the observation is enhanced. With respect to completeness, the documentary analysis of policy and/or resource documents added an additional dimension to the findings from the in-depth interviews, without straying from the research objectives. As health researchers continue to utilize qualitative methods in their work, developing strategies for establishing rigour and being transparent in their use becomes of utmost importance.

5.4 Policy Implications

In May 2013, Health Canada released an information update to the general public to reinforce the importance of food allergy awareness. The update describes the seriousness of anaphylaxis and the types of symptoms people may experience during an allergic response. There are also tips for protecting oneself against exposure to allergens; these include instructions on reading food labels under the new food allergen labelling regulation (Health Canada, 2013).

While the government should be recognized for its efforts in raising awareness, the findings of this thesis suggest that they still fall short. From the documentary analysis of policy and/or resource documents and key informant interviews, it was concluded that none of the major online resources for allergic individuals contains content that is tailored to new Canadians. Moreover, the participant interviews revealed that lower health literacy may be contributing to a higher perception of risk since terms such as “food intolerance” and “anaphylaxis” are not easily

understood among those for whom English is not a first language. Therefore, it is recommended that Health Canada and/or other leading Canadian organizations in allergy advocacy adopt a similar strategy to the Australian Society of Clinical Immunology and Allergy (ASCIA). The ASCIA has recently released anaphylaxis fact sheets in multiple languages, geared towards parents with allergic children (ASCIA, 2013). The fact sheets give a detailed description of what anaphylaxis is and the role of the doctor, parents, and school in protecting child safety (ASCIA, 2013). The fact sheets also provide website links to other reliable sources of information, including information on contacting a dietician or psychologist who specializes in anxiety management (ASCIA, 2013). To encourage such changes, a copy of this thesis will be sent to Anaphylaxis Canada, a leading advocacy group that supports all Canadians with food allergies.

5.5 Limitations

The aim of this thesis was to examine the gap between perceived risk of food allergy and estimates of prevalence in new Canadians. In doing so, the key findings demonstrate that there is a need to recognize the varied impacts and experiences of food allergy among new Canadians. The fact that food allergies are perceived to be increasing in prevalence underscores the pertinence of this issue. Moreover, immigrants represent a large and growing proportion of the Canadian population. Nevertheless, there are limitations of this thesis that deserve mention.

First of all, the perceptions held by key informants and participants were captured at one point in time. The participant's perception of risk may have been influenced by how long they have had a food allergy since management becomes easier over time for most individuals. Some participants had only recently developed a food allergy, while others had lived with a food allergy since they were a child. Given the small sample size, it was not possible to compare experiences according to time lived in Canada and/or time with a food allergy. Participants were

also asked to recall their first allergic experience and the feelings they felt at the time. This may have been affected by recall bias.

From a practical standpoint, time was a constraint on sampling and data collection. In order to have an even mix of mid- and long-term immigrants, participants were eligible as long as they were born in one of the many countries included in East and Southeast Asia. This broadened the scope of the sample when a narrow focus was desirable. For example, not all of the countries in East and Southeast Asia were represented by a participant. Although equal representation of country was not a recruitment objective, capturing all the cultural nuances within such a diverse region of the world like Asia would be impossible in a small sample. Fortunately, saturation was still reached with 18 participants. There was enough interest in the study to be able to recruit participants until no new themes emerged during the interviews.

With respect to methodological limitations, a mix of in-person and telephone interviews was conducted. One potential drawback to telephone interviews is that facial expressions of the participant cannot be observed. However, a study by Trier-Bieniek (2012) states that there is no significant difference in the quality of data between in-person and telephone interviews.

5.6 Directions for Further Research

Because of the exploratory nature of this thesis, there are two issues that deserve greater attention in future studies investigating trends and patterns in food allergy prevalence. Firstly, lower health literacy in immigrant populations may be contributing to a higher perception of risk. To address this, a knowledge translation piece in multiple languages on food allergies may be beneficial to researchers as well as the general public. Knowledge translation can be used to dispel misinformation about food allergies and strengthen the accuracy of self-reported measures.

Secondly, it is still unclear whether or not Canadian immigrants are less or more likely to have food allergies compared to non-immigrants. One possible direction to investigate this would be to conduct a longitudinal study of immigrants and their health status over time, with the inclusion of allergic diseases. A longitudinal study would also allow researchers to compare allergic experiences according to time lived in Canada and/or time lived with a food allergy. With respect to studies measuring prevalence of food allergy, researchers should recognize that immigrants may be allergic to a wider variety of allergens than those typically seen in Canada. Moreover, the diagnosis of food allergies and availability of epinephrine auto-injectors is less common in parts of East and Southeast Asia than in Canada, which is a challenge when measuring prevalence based on self-report.

Studies on food allergies have only recently gained traction in Asia, and therefore it is expected that awareness overseas will increase with time. These trends will be important to track, given that immigrants represent a large and growing proportion of the Canadian population. Subsequently, further research will also be necessary to inform and facilitate change at the policy level in order to protect allergic individuals in Canada and abroad.

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APPENDIX A

Household frequency data from SPACE (Soller et al., 2012)

Table 1: Type of food allergy reported (n=1,316)

Allergen	Frequency (%)
peanut	139 (10.56)
tree nut	132 (10.03)
fish	84 (6.38)
shellfish	220 (16.72)
sesame	21 (1.60)
milk	94 (7.14)
eggs	74 (5.62)
wheat	42 (3.19)
soy	22 (1.67)
other	488 (37.08)

Table 2: Top 20 countries of birth for individuals who reported a food allergy (n=10,898)

Country of Birth	Frequency (%)
Canada	8132 (74.62)
Philippines	543 (4.98)
India	470 (4.31)
China	194 (1.78)
Pakistan	190 (1.74)
Jamaica	163 (1.50)
Sri Lanka	159 (1.46)
United States	133 (1.22)
Bangladesh	114 (1.05)
Hong Kong	95 (0.87)
Germany	90 (0.83)
England	84 (0.77)
Guyana	83 (0.76)
Iran	80 (0.73)
Italy	68 (0.62)
Russia	65 (0.60)
Poland	64 (0.59)
Ukraine	58 (0.53)
United Kingdom	57 (0.52)
Trinidad	56 (0.51)

Table 3: Number of years lived in Canada of those born outside of Canada (n=4,457)

Years	Frequency (%)
Less than 10	1687 (37.85)
More than 10	2770 (62.15)

Table 4: Country of birth by Asian region (n=2,209)

Region	Frequency (%)
South Asia	975 (44.14)
Southeast Asia	651 (29.47)
East Asia	385 (17.43)
West Asia	185 (8.37)
Central Asia	13 (0.59)

Table 5: Countries of birth in Southeast Asia (n=651)

Country of Birth	Frequency (%)
Philippines	543 (83.41)
Vietnam	45 (6.91)
Indonesia	15 (2.30)
Malaysia	14 (2.15)
Burma	14 (2.15)
Cambodia	9 (1.38)
Laos	7 (1.08)
Thailand	4 (0.61)

APPENDIX B

Ethics Clearance

Dear Researcher:

The recommended revisions/additional information requested in the ethics review of your ORE application:

Title: Experiences and perceptions of food allergies in ethnocultural communities

ORE #: 18434

Faculty Supervisor: Susan J. Elliott

Student Investigator: Stephanie Lu

have been reviewed and are considered acceptable. As a result, your application now has received full ethics clearance.

A signed copy of the Notification of Full Ethics Clearance will be sent to the Principal Investigator or Faculty Supervisor in the case of student research.

Note 1: This ethics clearance from the Office of Research Ethics (ORE) is valid for one year from the date shown on the certificate and is renewable annually, for four consecutive years. Renewal is through completion and ethics clearance of the Annual Progress Report for Continuing Research (ORE Form 105). A new ORE Form 101 application must be submitted for a project continuing beyond five years.

Note 2: This project must be conducted according to the application description and revised materials for which ethics clearance has been granted. All subsequent modifications to the project also must receive prior ethics clearance (i.e., Request for Ethics Clearance of a Modification, ORE Form 104) through the Office of Research Ethics and must not begin until notification has been received by the investigators.

Note 3: Researchers must submit a Progress Report on Continuing Human Research Projects (ORE Form 105) annually for all ongoing research projects or on the completion of the project. The Office of Research Ethics sends the ORE Form 105 for a project to the Principal Investigator or Faculty Supervisor for completion. If ethics clearance of an ongoing project is not renewed and consequently expires, the Office of Research Ethics may be obliged to notify Research Finance for their action in accordance with university and funding agency regulations.

Note 4: Any unanticipated event involving a participant that adversely affected the participant(s) must be reported immediately (i.e., within 1 business day of becoming aware of the event) to the ORE using ORE Form 106.

Best wishes for success with this study.

Susanne Santi, M. Math.,
Senior Manager
Office of Research Ethics

APPENDIX C

In-depth Interview Guides

1. Key Informant (Public Health)

Experiences and perceptions of food allergy in new Canadians from Asia		
<p>Purpose: To understand how individuals from East and Southeast Asia perceive food allergies. To understand specific coping strategies and/or barriers that East and Southeast Asians face in managing food allergies.</p>		
Construct	Question	Probe
Participant Background	Tell me about your job.	What aspect of your job requires you to do work on food allergies?
	Are there any aspects of your job that require you to interact with new Canadians?	What about indirectly?
	Are you yourself new to Canada?	How long have you lived in Canada?
Public Health and New Canadians	What are the major challenges facing new Canadians when they arrive in the Region of Waterloo?	What might be some of their concerns related to health?
	What are the major health concerns you deal with on a daily basis in public health in the Region of Waterloo?	
Food Allergy Awareness and Policy	How knowledgeable are you about food allergies?	Where do you get your information from? Do you ever refer people to these resources?
	How familiar are you with food allergy policy and regulations?	Where do you get your information from? Do you ever refer people to these resources?
	Have you ever received information/letters/pamphlets/emails from the public health department or Health Canada on food allergy?	When were they issued? What kind of content did they have?
	Are you familiar with any educational material that has been created for new Canadians?	When were they issued? What kind of content did they have?
Food Allergies in Southeast Asia and China (or other ethnocultural groups if KI has	Do you think food allergies are common in Southeast Asia or China?	Who is affected? What kind of food allergies are there?
	What cultural role does food play in Southeast Asian countries or China?	

more knowledge about them)	What types of Southeast Asian or Chinese foods might not be safe for someone with a food allergy?	How do you think that impacts them?
	How would someone react if another person rejected their food because they had a food allergy?	Supportive, accepting, skeptical, indifferent
Managing Food Allergy	What do you think is the biggest challenge for new Canadians in managing their food allergy?	Getting support from families or friends, finding information in their language, reading food labels
	What changes do they have to make to their lifestyle to cope?	
Final	Of all the things we discussed today, what to you is the most important? <i>Summarize purpose of study and main points. Is this an adequate summary?</i>	
	Is there anything else you'd like to add that we haven't already talked about?	

2. Key Informant (Allergist)

Experiences and perceptions of food allergy in new Canadians from Asia		
Purpose: To understand how individuals from East and Southeast Asia perceive food allergies. To understand specific coping strategies and/or barriers that East and Southeast Asians face in managing food allergies.		
Construct	Question	Probe
Participant Background	Tell me about your job.	
	Can you please tell me about the aspects of your job that require you to interact with new Canadians?	
	Have any aspects of your extensive training ever dealt with working with visible minorities/vulnerable populations?	
	Are you yourself new to Canada?	How long have you lived in Canada?
Allergy Practice in Region of Waterloo	How many other allergists are there in the Region of Waterloo?	
	Approximately how many patients in total are covered by these clinics?	
Demographics of Clinic	Approximately what percentage of your practice is made up of visible minorities?	What ethnicities are most prevalent in your practice?
	Would this percentage differ if you were outside the Region of Waterloo?	How so?
Food Allergy Awareness & Education	What are your primary methods for staying up to date with food allergy research? What sources do you turn to?	
	How often do you receive information/letters/pamphlets/emails from the public health department or Health Canada on food allergy?	When were they issued? What kind of content do they have?
	Are you familiar with any educational material that has been created for new Canadians?	When were they issued? What kind of content did they have?
Food Allergies in New Canadians	Do new Canadians ask you about food allergies?	What kind of questions do they ask? Give examples. What do you tell them?
Food Allergies in Southeast Asia and China	Do you think food allergies are common in Southeast Asia and China?	Who is affected? What kind of food allergies are there?
	Are you aware of the cultural role that food plays in Southeast Asian countries and China?	
	What types of Southeast Asian foods might not be safe for someone with a food allergy?	How do you think that impacts them?

	How would someone react if another person rejected their food because they had a food allergy?	Supportive, accepting, skeptical, indifferent
Managing Food Allergy	What do you think is the biggest challenge for new Canadians in managing their food allergy?	Getting support from families or friends, finding information in their language, reading food labels
	What changes do they have to make to their lifestyle to cope?	
Final	Of all the things we discussed today, what to you is the most important? <i>Summarize purpose of study and main points. Is this an adequate summary?</i>	
	Is there anything else you'd like to add that we haven't already talked about?	

3. Participant

Preamble

Good morning/afternoon. Thank you for taking the time to join me today to talk about your perceptions and experiences with food allergies. My name is Stephanie and I am a Master's student from the School of Public Health and Health Systems at the University of Waterloo.

The purpose of this study is to capture the views of new Canadians who have an allergic member in their household through the use of in-depth interviews. Knowledge and information generated from this study will help contribute to our current understanding of food allergies by identifying any unmet needs faced by new Canadians who have a food allergy.

You were invited to this interview because you yourself or a member of your household has a food allergy. You are also of East or Southeast Asian descent, which is the chosen ethnocultural community of focus for my study. Your interview today will help us understand some of the similarities and differences in your perceptions and experiences with food allergies. There are no wrong answers.

I am recording this session because I don't want to miss any of your comments. I ask that you turn off your phone or pager for the next hour. You may be assured of complete confidentiality.

Experiences and perceptions of food allergy in new Canadians from Asia		
Purpose: To understand how individuals from East and Southeast Asia perceive food allergies. To understand specific coping strategies and/or barriers that East and Southeast Asians face in managing food allergies.		
Construct	Question	Probe
Participant background/ Establishing Place	Can you please tell me where you were born and for how long you have lived in Canada?	Who did you move here with? How long have you been at your current residence?
	Why did you choose to come to Canada?	Why did you choose to live in the Region of Waterloo?
	What do you like about living in Canada? Region of Waterloo?	Have there been any surprises or challenges you've experienced here that you didn't expect?
	Who in your family has a food allergy?	When and where were they diagnosed? How long had they lived in Canada?
	Did the allergic individual have the food allergy in [country of origin] or did it develop here?	
	<i>If it's a child:</i> How many children do you have in your family?	How old were they when you moved to Canada? What are they allergic to?

Allergy Experiences	How did you know they had a food allergy?	Were you already familiar with food allergies?
	Do they have any other reactions?	What type? What kind of reaction did they have? Were they hospitalized?
	Has the allergy been diagnosed by a doctor? What was that like?	Did they provide you with information about food allergies?
Allergy Management	Does [allergic member in household] carry an epi-pen? Wear a medic-alert bracelet?	For how long? Ever administer? Where is it kept? Cost, affordability, insurance coverage?
	Who is your primary care provider with regards to the [allergic member in household]'s allergy?	MD, ND, nurse practitioner, hospital, pediatrician, allergist, other Ability to access?
	Have you made changes in the home since [allergic member in household] was diagnosed/had reaction?	Avoidance, reading food labels, limited guests
	Have you made changes when you go outside the home because of the food allergy?	School, other homes, public space, social events
	Is it easy to deal with [allergic member in household]'s allergy? What is the biggest challenge?	Support, cost, knowledge, food labelling
	Which environments do you think are safest for [allergic member in household]?	Home, school, family/friends homes, public space
	Are there environment that you are less comfortable in?	Home, school, family/friends homes, public space
Support and Coping	Do you feel supported in dealing with [allergic member in household]'s food allergies? Who is most supportive?	Partner, family, friends, teachers, community organization
	What about our public health department in the Region of Waterloo? Your allergist? Family doctor?	
	<i>If it's a child:</i> How did [other parents] respond to diagnosis of [child]'s allergy?	Supportive, accepting, skeptical, indifferent
	How did other family members respond? Friends?	Supportive, accepting, skeptical, indifferent
	Do you know other families who are dealing with a food allergy?	Do you see them often?
	What is your biggest source of worry?	
	What would make things easier for you and [allergic member in household]?	
Sources of Information	If you had a question about food allergies, where/who would you ask?	

	Were you aware of food allergies before you came to Canada? Did you know others with food allergies? How does this compare to allergies in Canada?	
	What resource/program/service do you think would be helpful for other parents and children dealing with allergies?	
Final	Of all the things we discussed today, what to you is the most important? <i>Summarize purpose of study and main points. Is this an adequate summary?</i>	
	Is there anything else you'd like to add that we haven't already talked about?	

Closing Remarks

Thank you for sharing your knowledge and stories with me today. If you ever have any questions about the research I am doing, you may reach me by e-mail (s4lu@uwaterloo.ca). Again, I want to assure you that none of the names you have mentioned will be used in my report. I sincerely hope that this study will help identify any unmet needs faced by new Canadians who have a food allergy. This would not be possible without your participation today – thank you.

APPENDIX D

Recruitment Agencies

1. Anaphylaxis Canada
2. Central Ontario Chinese Cultural Centre (COCCC)
3. Chinese Student Association, University of Waterloo
4. CMAS
5. Conestoga College LINC English School
6. Immigration Partnership
7. Kitchener Downtown Community Health Centre
8. K-W Multicultural Centre
9. K-W YMCA Settlement Services
10. Laurel Creek Neighbourhood Association
11. Thai Students Association, University of Waterloo
12. Region of Waterloo Public Health
13. Renison University College, University of Waterloo
14. United Filipino-Canadian Society of Waterloo Region
15. Waterloo Region Chinese Community Association
16. Waterloo Region Anaphylaxis Support & Education (WRASE)
17. YMCA Immigrant Services
18. YWCA LINC Kids

GOT A FOOD ALLERGY?

ARE YOU A NEW CANADIAN OF EAST OR SOUTHEAST ASIAN DESCENT*?

- *Participate in a 30 min. interview to talk about your experiences*
- *Receive a \$20 gift card to Starbucks*

**For more information, please contact:
Stephanie Lu
School of Public Health and Health Systems
519-888-4567 Ext. 33682
s4lu@uwaterloo.ca**

*Southeast Asian countries include the Philippines, Vietnam, Thailand, Indonesia, Malaysia, Burma (Myanmar), Cambodia, Laos, Singapore, and Brunei. East Asian countries include China, Japan, Korea, and Taiwan.

This study has been reviewed by, and received ethics clearance through, the Office of Research Ethics, University of Waterloo.

APPENDIX E

Participant Information Letter

Dear [participant],

This letter is an invitation to consider participating in a study I am conducting as part of my Master's degree in the School of Public Health and Health Systems at the University of Waterloo under the supervision of Professor Susan J. Elliott. My study aims to capture the views of new Canadians of Southeast and East Asian heritage that either have a food allergy of their own or lives with someone who does. Knowledge and information generated from this study will help contribute to our current understanding of food allergies by identifying any unmet needs faced by new Canadians who have a food allergy.

Participation in this study is voluntary. Your role will be to share your perceptions of food allergy risk as well as your experiences in managing a food allergy. This will involve an in-person interview of approximately 30 min. on campus. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw from this study at any time without any negative consequences by advising the researcher. With your permission, the interview will be audio recorded to facilitate collection of information, and later transcribed for analysis. All information you provide is considered completely confidential. With your permission, anonymous quotations may be used in my thesis or relevant publications, but your name will not appear. In addition, data collected during this study will be retained for 2 years under lock in the School of Public Health and Health Systems at the University of Waterloo. Data will not contain personal identifiers and only researchers associated with this project will have access to it. There are no known or anticipated risks to you as a participant in this study. In appreciation of your time given to this study we will provide you with a \$20 gift card to the Starbucks Coffee Company. The amount received is taxable. It is your responsibility to report this amount for income tax purposes

To be eligible for participation, you must also be 18 years of age or older, feel comfortable speaking English, and have permanent resident status in Canada.

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact me at 519-888-4567, Ext. 33682 or by email at s4lu@uwaterloo.ca.

I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. However, the final decision about participation is yours. Should you have comments or concerns resulting from your participation in this study, please contact Dr. Maureen Nummelin in the Office of Research Ethics at 1-519-888-4567, Ext. 36005 or maureen.nummelin@uwaterloo.ca.

I very much look forward to speaking with you and thank you in advance for your assistance in this project.

Yours sincerely,
Stephanie Lu
University of Waterloo
519-888-4567 Ext. 33682
s4lu@uwaterloo.ca

CONSENT FORM

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Stephanie Lu of the School of Public Health and Health Systems at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that my interview is to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

In appreciation of my time given to this study I am aware that I will receive a \$20 gift card to the Starbucks Coffee Company provided that I complete the interview.

This project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

YES NO

I agree to have my interview audio recorded.

YES NO

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

YES NO

Print Name

Signature

Witness

Date

APPENDIX F

Demographic Questionnaire

The information you provide us with in this questionnaire will not be linked with your name. This information is being gathered to create a demographic profile of the participants in this study.

Please circle the appropriate choice and complete the description boxes.

1. What is your sex?

Male

Female

2. What is your age?

18-21 years

22-25 years

26-30 years

31-40 years

41-50 years

51-60 years

61 or over

3. Where were you born?

Southeast Asia:

Philippines

Vietnam

Thailand

Indonesia

Malaysia

Cambodia

Laos

Singapore

Brunei

Burma

East Asia:

China

Japan

Korea

Taiwan

Hong Kong

Other:

4. How long have you lived in Canada?

< 5 years

< 10 years

< 20 years

21 years or over

5. What is the highest educational degree you have completed?

Graduate Diploma/Certificate

Undergraduate Diploma/Certificate

Bachelors degree

Masters degree

Doctorate

Professional degree

6. What is your current (or most previous) occupation?

7. What food(s) are you allergic to?

8. How old were you when you were diagnosed with a food allergy?

Thank you!

Please submit questionnaire to Stephanie Lu, University of Waterloo.

APPENDIX G

Coding Manual for Participant Interviews

(1) Background

- Birth Place
 - China [BC1]
 - Hong Kong [BC2]
 - Malaysia [BC3]
 - Philippines [BC4]
 - Thailand [BC5]
 - Vietnam [BC6]
 - Other [BC7]
- Years in Canada
 - < 5 [YC1]
 - < 10 [YC2]
 - < 20 [YC3]
 - > 21 [YC4]
- Reasons for Immigrating
 - Education [IM1]
 - To join family [IM2]
 - Occupation [IM3]
 - Quality of life [IM4]
- Immigration Experience
 - Likes [IME1]
 - Dislikes [IME2]
 - Surprises [IME3]
 - Challenges [IME4]
- Allergic Member
 - Self [AM1]
 - Son [AM2]
 - Daughter [AM3]
- Participant's Age
 - 18-21 [AGE1]
 - 22-25 [AGE2]
 - 26-30 [AGE3]
 - 31-40 [AGE4]
 - 41-50 [AGE5]
- Other Medical Conditions [OMC]
- Allergic Member's Age (if not "Self")
 - < 2 [AAGE1]
 - 2-4 [AAGE2]
 - 5-7 [AAGE3]
 - 8-10 [AAGE4]
 - > 11 [AAGE5]
- Allergic Member's Birth Place (if not "Self") [ABC]

(2) First Allergic Experience

- Age of 1st Reaction [AGEF1]

- < 5 [AGEF2]
- 5-10 [AGEF3]
- 11-18 [AGEF4]
- > 18
- Allergen
 - Egg [EGG]
 - Fish [FSH]
 - Fruit [FRT]
 - Peanut [PNT]
 - Shellfish [SHF]
 - Shrimp [SHP]
 - Other [OTH]
- Symptoms
 - Hives [SYM1]
 - Rashes [SYM2]
 - Restricted airway [SYM3]
 - Swelling [SYM4]
 - Other (e.g. Itchiness) [SYM5]
- Severity
 - No medication required [SEV1]
 - Physician-administered medication [SEV2]
 - Self-administered medication [SEV3]
 - Hospitalization [SEV4]
 - Anaphylactic [SEV5]
- Diagnosis
 - Self [DN1]
 - Nurse [DN2]
 - Physician [DN3]
 - Allergist [DN4]
- Diagnostic Test
 - Skin Prick Test [DNT1]
 - Blood Test [DNT2]
 - Other [DNT3]
- Feelings Associated with 1st Reaction (includes parents if not “Self”)
 - Surprise [FE1]
 - Skeptical [FE2]
 - Scared [FE3]
 - Quick acceptance [FE4]
 - Slow acceptance [FE5]
 - Disappointment [FE6]
 - Relief [FE7]
 - Other [FE8]

(3) Consequent Allergic Experiences

- Emergent Allergy
 - Yes [EA1]
 - No [EA2]
- Discontinued Allergy
 - Yes [DA1]
 - No [DA2]

- Accidental Exposure
 - Yes [AEX1]
 - No [AEX2]
- Additional Diagnosis
 - Yes [ADN1]
 - No [ADN2]

(4) Allergy Management

- Epi-Pen
 - Yes [EPI1]
 - No [EPI2]
- Medic-Alert Bracelet [MAB]
- Medication
 - Benadryl [MED1]
 - Alternative medicine [MED2]
 - Other [MED3]
- Oral Immunotherapy [OI]
- Strategies
 - Avoidance
 - Sometimes [SGA1]
 - Every time [SGA2]
 - Prior Experience with Food [PEXP]
 - Food Labels
 - No reliance [FL1]
 - Some reliance [FL2]
 - Heavy reliance [FL3]
- Changes Inside the Home
 - Grocery shopping [HOM1]
 - Cooking [HOM2]
- Changes Outside the Home
 - Restaurants [OUT1]
 - School [OUT2]
 - Social gatherings [OUT3]
- Comfort Level with Allergen
 - Cannot be in household [COM1]
 - Prefer not to have in household [COM2]
 - Can be consumed in household [COM3]
- Allergy Management Specific to Children [CLD]

(5) Support and Caring

- Family's Attitude Towards Allergy
 - Surprise [FMA1]
 - Skeptical [FMA2]
 - Scared [FMA3]
 - Quick acceptance [FMA4]
 - Slow acceptance [FMA5]
 - Disappointment [FMA6]
 - Relief [FMA7]
 - Supportive/Cautious [FMA8]
 - Other [FMA9]

- Friend's Attitude Towards Allergy
 - Surprise [FRA1]
 - Skeptical [FRA2]
 - Scared [FRA3]
 - Quick acceptance [FRA4]
 - Slow acceptance [FRA5]
 - Disappointment [FRA6]
 - Relief [FRA7]
 - Supportive/Cautious [FRA8]
 - Other [FRA9]

(6) Quality of Life

- Canadian Lifestyle (work conditions, living conditions, amount of physical activity, etc.)
 - Similarities with birth place [LSS]
 - Differences with birth place [LSD]
 - Improved lifestyle habits in Canada [LSI]
 - Worsened lifestyle habits in Canada [LSW]
- Canadian Environment
 - Similarities with birth place [EVS]
 - Differences with birth place [EVD]
 - Improved environment in Canada [EVI]
 - Worsened environment in Canada [EVW]
- Canadian Diet
 - Similarities with birth place [DTS]
 - Differences with birth place [DTD]
 - Improved characteristics of diet in Canada [DTI]
 - Worsened characteristics of diet in Canada [DTW]
- Cultural Cuisine
 - Characteristics of food eaten in birth place [CCB]
 - Consumption of traditional foods in Canada [CCC]
 - Accessibility of traditional foods in Canada [CCA]
 - Level of safety compared to western cuisine [CCS]
 - Level of preference compared to western cuisine [CCP]
- Primary Safety Concerns about Allergy and Level of Worry Associated with it
 - Little worry [PSC1]
 - Worrisome [PSC2]
 - Anxious [PSC3]
 - Very anxious [PSC4]
 - Lessened worry over time [PSC5]
 - Increased worry over time [PSC6]
- General Attitude Towards Allergy
 - Positive [GAT1]
 - Negative [GAT2]
 - Neutral [GAT3]
- Overall Impact of Allergy on QOL
 - Negligible [QOL1]
 - Noticeable [QOL2]
 - Significant [QOL3]

(7) Food Allergy in Southeast and East Asia (vs. Canada)

- “Food Allergy” in Other Languages [LAN1]
 - Chinese (Mandarin/Cantonese) [LAN2]
 - Filipino [LAN3]
 - Malay [LAN4]
 - Thai [LAN5]
 - Vietnamese [LAN6]
 - Other
- Perceived Prevalence in Birth Place
 - Lower [PRV1]
 - Same [PRV2]
 - Higher [PRV3]
- Perceived Etiology of Food Allergy (for general population)
 - Diet [ET1]
 - Genetics [ET2]
 - Hygiene hypothesis [ET3]
 - Other [ET4]
- Perceived Etiology of Food Allergy (for personal allergy, if different from “general population”)
 - Diet [ETP1]
 - Genetics (discussion about family history) [ETP2]
 - Hygiene hypothesis [ETP3]
 - Unknown [ETP4]
 - Other [ETP5]
- Level of Awareness in Birth Place
 - Lower [LA1]
 - Same [LA2]
 - Higher [LA3]
 - Increasing [LA4]
- Indicators of Level of Awareness (or Lack thereof) in Birth Place
 - Education [ILA1]
 - Food labelling [ILA2]
 - Health promotion [ILA3]
 - Media [ILA4]
 - Policies [ILA5]
 - Restaurants [ILA6]
 - Food allergy terminology [ILA7]
- Explanations for Existing Level of Awareness/Perceptions on Food Allergy in Birth Place
 - Education [EX1]
 - Genetics [EX2]
 - Perceived prevalence [EX3]
 - Health priorities [EX4]
 - Availability of diagnostic testing [EX5]
 - Other [EX6]
- Perception of Risk in Birth Place
 - Lower [POR1]
 - Same [POR2]
 - Higher [POR3]

- Level of Difficulty when Coping with Allergy in Birth Place
 - Easier [COP1]
 - Harder [COP2]
 - Same [COP3]
- Obstacles to Managing Allergy in Birth Place
 - Different eating habits [OB1]
 - Different attitudes towards food [OB2]
 - Less accommodative (restaurants, schools) [OB3]
 - Different health safety standards [OB4]
 - Other [OB5]
- Existing Policies in Birth Place
 - Not aware of any policies [POL1]
 - Aware of some policies [POL2]
 - Same types of policies as in Canada [POL3]
- Attitude Towards Increasing Awareness in Birth Place
 - Unnecessary [AW1]
 - Probably necessary [AW2]
 - Definitely necessary [AW3]
- Suggestions for Addressing Food Allergies in Birth Place [SUG]

(8) Sources of Allergy Information

- Information Given Upon Diagnosis
 - None [INF1]
 - Pamphlet [INF2]
 - Handout/Fact Sheet [INF3]
 - Other (e.g. Unsure) [INF4]
- Physician
 - Trusted [IF1T]
 - Not trusted [IF1N]
 - Helpful [IF1H]
 - Unhelpful [IF1U]
- Allergist
 - Trusted [IF2T]
 - Not trusted [IF2N]
 - Helpful [IF2H]
 - Unhelpful [IF2U]
- Community/Public Health Services
 - Trusted [IF3T]
 - Not trusted [IF3N]
 - Helpful [IF3H]
 - Unhelpful [IF3U]
- Advocacy Groups
 - Trusted [IF4T]
 - Not trusted [IF4N]
 - Helpful [IF4H]
 - Unhelpful [IF4U]
- Personal Research
 - Yes [IF5Y]
 - No [IF5N]