

**A Hermeneutic Phenomenological Inquiry of the Lived Experience of Food Allergy within
the School Environment: Perspectives from Children, Youth, and Parents**

by

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Abstract

Food allergy (FA) affects over three million Canadians, representing almost 8% of the population. Increased awareness has highlighted significant burdens associated with FA, including anxiety and diminished quality of life among children and youth with FA, and their parents. Despite this, there remains a paucity of research exploring lived experiences of FA, particularly at school. The purpose of this study was to develop a deeper understanding of the lived experiences of children and youth with life-threatening FA, and their parents within their everyday environments and relationships, with an emphasis on the school environment. A hermeneutic phenomenological approach informed by the Ecological Systems Theory was used, and was further complemented by ecomaps, an art-based activity, to guide data collection and analysis. A total of 21 participants: children (n = 4), youth (n = 5), and parents (n = 12) volunteered to take part in this study. Data sources included transcripts of two digitally recorded interviews per participant, participants' ecomaps, and fieldnotes. Data were analyzed iteratively through hermeneutic phenomenological methods. Guided by van Manen's existentials, five themes were captured: *Safety as Part of Who I Am and What I Do*, *Safety Through Communication and Understanding*, *Seasons of Safety*, *Holding Safety in Place*, and *Living Safely Through Things*. Collectively, these themes contribute to the overarching theme of the study, *Striving for Safety*. These findings add depth and extend our current understanding of the experiences of Canadian children and youth with life-threatening FA, and their parents underscoring the need for optimal safety, inclusion, psychosocial support, and school-wide education. Furthermore, it offers insights to inform school policy, FA education, and future research with the goal of fostering environments that promote both safety and belonging for families living with FA.

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Dedication

This dissertation is dedicated to the children, youth, and parents affected by food allergy who generously shared their time, experiences, and recommendations on how schools can optimize food allergy safety. Your trust and openness to share your food allergy journey have contributed to the depth of understanding and given meaning to this research. I also dedicate this research to my family— this would not have been possible without your love, support, encouragement, and patience throughout the years. And to Leo, our beloved golden retriever, whose loyal presence kept me going through every phase of my PhD. You truly are the “bestest boy”!

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Chapter 1

Introduction

To ensure a well-constructed research study, I followed Crotty's (1998) scaffolded approach to outline the research process. According to Crotty, once the research purpose and objectives are established four key elements must be addressed: epistemology, theoretical perspective, methodology, and methods (See Appendix A). It is the intent that addressing these four elements of the research process situates the research question(s) in an epistemological stance, theoretical perspective, methodology, and methods that all align and inform one another. In doing so, transparency and accountability were fostered for this qualitative study (Crotty, 1998; Wener & Woodgate, 2013). A summary of the research design is provided in Appendix B.

In this chapter, I articulate the research purpose and research questions. The focus of Chapter 2 is a literature review of located relevant research related to the study's purpose. In Chapter 3, the epistemological assumptions and theoretical perspectives are presented to provide the theoretical foundation for this research. Chapter 4 continues Crotty's (1998) scaffolded approach by outlining the research methodology and methods employed in this study. Chapter 5 presents the participant demographic profile, while Chapter 6 focuses on the research findings. Finally, Chapter 7 discusses the findings in relation to the current literature and as well, offers recommendations for future research, education, and policy.

Statement of the Problem

Food allergy (FA) has been on the rise for the last two decades and has become a global public health issue (Harrington et al., 2012; Peters et al., 2021). FA affects approximately 8% of children aged 5–17 years (Sicherer, 2011; Food Allergy Canada, 2024) in the US and Canada, with the rate of FA having increased by 50% between 1999 and 2011 (Feng & Kim, 2019; Gupta

et al., 2011; Sicherer, 2017). The rise in prevalence of FA in children has been referred to by some as a 21st century epidemic (Dean et al., 2016; Waggoner, 2013). According to Food Allergy Canada (2024) over 600,000 children under the age of 18 live with a FA, and perhaps even more striking are estimates that up to 50% of Canadian households are impacted in some way by FA (Food Allergy Canada & Canadian Society of Allergy and Clinical Immunology [CSACI], 2019).

FA is a complex, chronic medical condition defined as an abnormal immune response to a specific food (Sanagavarapu, 2018). At present, there is no cure for FA and management includes strict avoidance of the known allergen and prompt treatment of anaphylaxis with epinephrine should exposure occur (Quach & John, 2018). Anaphylaxis is defined as a severe systemic allergic reaction and symptoms may include hives, swelling of the lips and tongue, difficulty breathing or swallowing, and symptoms of shock which can be fatal (Food Allergy Canada & CSACI, 2019; Jones & Wesley Burks, 2017). Emergency department visits for food-induced anaphylaxis in the US increased 285% between the years of 2005–2014 for children between 5–17 years of age (Motosue et al., 2017). Parents and children or youth with a FA bear the primary responsibility and burden of FA management, requiring constant vigilance to minimize the risk of allergen exposure.

The rise in prevalence of FA has resulted in an increased research focus related to a myriad of quality of life (QoL) issues experienced by families affected by FA such as psychological and social concerns, and as well, financial burdens associated with a FA (Moen et al., 2019; Sharma & Herbert, 2015). More specifically, reports of anxiety, stress, and fears related to FA and its management are reported by children, youth, and their parents (Polloni & Muraro, 2020).

Need to Better Understand Children and Youth Experiences at School

Spending a significant portion of their day at school, children and youth with life-threatening FA are at risk for allergen exposure, particularly during meals and snacks, underscoring the importance of effective and safe FA policies and practice at school (Wasserman, 2021). According to White and colleagues (2016), “food was the most commonly identified anaphylaxis trigger across grade levels, seasons, and geographic regions” (p. 286). Between 16–18% of children with a FA have reported at least one allergic reaction while at school (Egan & Sicherer, 2016) and almost 25% of students with no previous history of allergy experience anaphylaxis for the first time at school (Sicherer & Mahr, 2010; White et al., 2016, 2017, Food Allergy Canada, 2024). Although it is difficult to ascertain current rates of fatalities in schools, a case series report from the US estimated that 9 of 32 fatalities that did occur in schools were linked to a delay in epinephrine administration (Bock et al., 2001).

According to Bock and colleagues (2001, 2007), youth with a life-threatening FA pose the highest risk for adverse reactions, including death due to anaphylaxis. This risk may be attributed to their developmental stage and/or FA policies in high schools. At a time when youth are tasked with an increased responsibility for the management of their FA, they are entering a stage of peer-approval seeking, impulsivity, and risk-taking (Gupta, 2014; Mustafa & Bess, 2018; Sampson et al., 2006). Further, school policies about FA can be more ambiguous or may be less enforced during middle and high school when compared to elementary schools (Dupuis et al., 2020). Children and youth with a FA can have variable levels of allergy education and confidence about self-management and may exhibit fear and anxiety about having a potential reaction at school (Sanagavarapu, 2018).

Knowledge and experience about a FA can vary with other students, teachers, and staff in schools (Ercan et al. 2012; Feldman et al., 2024; Sanagavarapu et al., 2025; Santos et al., 2023; Wasserman et al., 2021). Varying attitudes, knowledge, and misperceptions about FA within the school environment can impact the experiences of children and youth with a FA (Stjerna, 2015). In a study about FA awareness in schools, limited awareness of FA was associated with underdeveloped school policies and a lack of engagement and empathy from teachers and families without a FA (Dupuis et al., 2020). As a result, youth with FAs and their parents experienced additional stress and felt compelled to engage in coping strategies and self-advocacy for both protection and inclusion at school. More recently, Santos and colleagues' inquiry of teachers' perspectives on FA management highlighted variable levels of confidence and perceived knowledge amongst teaching staff and identified concerns about a lack of standardization and inconsistent enforcement of FA policies within different schools.

FA can present challenges for children and youth with a FA within the school environment such as stigma, social isolation, or exclusion (Dean et al., 2016), and bullying (Brown et al., 2021). Reports suggest FA-related bullying affects 20–53% of children or youth 5–19 years of age, yet few teachers report awareness of these incidents (Brown et al., 2021; Cooke et al., 2021; Fong et al., 2017; Polloni et al., 2016). Children and youth with a FA may be up to twice as likely to be bullied by their peers, contributing to anxiety, depression, and reduced self-esteem (Muraro et al., 2014; Shemesh et al., 2013). Exploring the lived experiences of children and youth with a life-threatening FA, and their parents will allow for a better understanding which may translate into recommendations to enhance school life.

Lack of Standardized FA Policies in Schools

In Canada, because health and education fall under provincial regulations, policies about FA management in schools are inconsistent across the country (Food Allergy Canada, 2020). In 2003, a 13-year-old Ontario student, Sabrina Shannon, died from cross contamination of food products in the school cafeteria resulting in a fatal allergic reaction (Dean et al., 2016). In response, Ontario passed landmark legislation in 2005, Sabrina's Law or *Bill 3* (Ontario Laws) which required all school boards in the province of Ontario to implement an anaphylaxis policy that includes staff training on how to manage anaphylactic reactions, develop emergency plans for each student with a FA, and outline emergency procedures in the event of a severe allergic reaction occurring in school (Dean et al., 2016; Murdoch et al., 2018). Since then, similar legislation or provincially mandated school policies have been enacted across Canada (Feldman et al., 2024; Murdoch et al., 2018).

Guidelines and expert opinions on best practices related to the management of FA in schools continue to evolve (Abrams et al., 2020; Greenhawt, 2020; Waserman et al., 2021). Parents of children with a FA report feeling better supported and less anxious in schools with legislation about FA when compared to schools in a non-legislated environment. Despite this, school health policies related to FA management in schools remain varied and inadequate (Cicutto et al., 2012). Interestingly, the implementation of some school policies designed to keep children and youth safe may result in unintended consequences. For example, although not required under Sabrina's Law or similar legislation across Canada, some school board policies have led to the segregation of children (aged 8–12 years) and youth (aged 13–17 years) with food allergies (FA) at separate tables or designated areas during lunch or snack times. Although such practices may reduce exposure to allergens, they can also result in students feeling “othered,”

excluded, and/or isolated (Dean et al., 2016; Elliot et al., 2015). Feelings of social isolation and exclusion by youth at school was related to feeling different than their peers, being segregated at allergen free tables, or being excluded from celebratory events (Dupuis et al., 2020). An in-depth exploration of these lived experiences for children and youth with a life-threatening FA, and their parents in Canadian schools will allow for a better understanding of experiences related to current school policy about FA and may help identify areas where further education and policy changes may be necessary to provide optimal support, inclusion, and safety for these families.

Current State of FA Research and Identified Gaps

The rise in prevalence of FA combined with the recognition of the psychosocial toll it can have on families, has led to an upsurge of research focusing on the impact of FA on quality of life (Dunn Galvin & Hourihane, 2016; Moen et al., 2019; Valero-Moreno et.al., 2024). Over the last 20 years, research attention on the mental health aspects of FA has increased, with varying emphasis on anxiety, worry, depression, psychological distress, and its psychosocial impact (Procter et al., 2021). However, these quantitative and qualitative studies have wide variation in their focus and methodology, often lack conceptual clarity, and/or fail to articulate a theoretical framework (Polloni & Muraro, 2020). This variability and conceptual blurring make generalizations about anxiety and other mental health impacts related to FA more challenging.

Despite the increased output of research, gaps in our knowledge about the experiences of children and youth remain. Both quantitative and qualitative research define the age parameters of children and youth differently, which can hinder drawing comparisons. For instance, some studies use the terms school-age generically without specific identifying age parameters (Egan & Sicherer, 2016; Sicherer & Mahr, 2010; Zavell, 2019), while others specify age parameters for children and youth but vary in their age definitions (Dean et al., 2016; Muraro et al., 2014).

Though some experiences of having a FA may remain constant throughout a child's school years, certain developmental differences and experiences may be specific to younger children who require more adult support when compared to older youth who are increasingly independent and assume more responsibility for their own FA management.

Quantitative studies about the QoL in children and youth with FA have wide variability in scope and design and are not well suited to capture complex phenomena. Often, the concept of quality of QoL is defined by the type of measurement tool used and as a result, does not offer a rich understanding of the experiences of children and youth with a FA, or their parents (Polloni & Muraro, 2020). Although the development of a various tools to measure or assess the impacts of FA on children or youth and parents can move our understanding forward, the wide range of tools used makes it difficult to make generalizations and comparisons across studies.

Qualitative studies about FA in children or youth, and their parents often fail to explicitly outline their epistemological and theoretical roots (Polloni & Muraro, 2020). According to Lopez and Willis (2004), an ongoing concern with many qualitative studies is the failure to clearly articulate the alignment between the method and its philosophical underpinnings which can lead to ambiguity in a study's purpose, structure, and interpretations of results. The absence of an explanatory framework guiding research may limit the ability of researchers, health care providers, and policy makers to fully understand, predict, and evaluate the impacts of FA (Dunn Galvin et al., 2009).

There remains a paucity of qualitative research about the overall lived experiences of children and youth with a FA, and their parents in schools from a Canadian perspective. International studies that focus on children, youth, and parents within the school environment may not translate to shared experiences of children or youth, and their parents in Canada (Dupuis

et al., 2020; Sanagavarapu, 2018; Stockhammer et al., 2020). In Canada, Feldman and colleagues (2024) engaged in a qualitative study exploring the perspectives about FA among children in kindergarten to Grade 8, both with and without a FA, to inform the development of an educational program about FA for schools. While this study offers a valuable Canadian perspective, it does not articulate its epistemology or theoretical framework, offers limited depth about FA experiences, and does not include parent perspectives. Abrams et al. (2020) conducted a qualitative Canadian study about parents of children with a FA (aged 0.6–16 years); however, its focus was on FA policy issues in Canada. Although this study provides insights into important policy considerations, it does not delve into the lived experiences of FA at school. Several qualitative studies published in Canada (Dean et al., 2016; Elliot et al., 2015; Fenton et al., 2011; 2013) offer valuable perspectives from children (aged 8–12 years) and youth (aged 13–17) about FA in school; however, all of these publications are based on the same data set from 2008, three years after Sabrina’s Law was passed in Ontario. Developing a contemporary understanding of FA within today’s school environments, nearly two decades after the enactment of Sabrina’s Law and amid widespread FA policy implementation across Canada, would be a valuable contribution to advancing current knowledge of FA experiences.

Despite the growing body of research, further exploration of the experiences of children, youth, and parents within Canadian school environments remains necessary. Given the lack of conceptual clarity and variable methodology in some prior research, care will be taken to clearly articulate this study’s theoretical foundations and methodology to ensure confidence in its findings. Further examination of school policies related to FA, and how these policies shape lived experiences, is warranted. Additionally, the COVID-19 pandemic and associated public

health restrictions significantly affected the school environment (Santos et al., 2022); understanding their impact on FA management may also prove valuable.

Purpose of the Study

The purpose of this research was to arrive at deeper understanding of the lived experiences of FA within the school environment from the perspectives of children (ages 8–11) and youth (ages 12–19) with a FA, and their parents in Canada.

Research Questions

To achieve this purpose, the following research questions will guide this study:

1. What are the lived experiences within the school environment like for children (ages 8–11) and youth (ages 12–19) with a FA?
2. What is it like to be a parent or caregiver of a child or youth with a FA within the school environment?
3. How do individual, relationships, community, and societal factors shape the lived experience of children and youth with a FA, and their parents within the school environment?
4. How has the COVID-19 pandemic's public health restrictions influenced the lived experience of children and youth with a FA, and their parents within the school environment?
5. What recommendations do children and youth with a FA, and their parents have to best support them through their experiences within the school environment?

Definition of Terms

For the ease of reading, please see Table 1 for common terms and definitions that were used throughout the thesis.

Table 1

Definition of Terms

Anaphylaxis	A systemic, acute, potentially fatal allergic reaction that can occur rapidly after contact with an allergen (Sicherer et al., 2010).
Child(ren)	For this study, a child (or children) refers to any school-age student(s) from ages 8–11 years of age, unless otherwise specified.
Emergency Anaphylaxis Plan (EAP)	A documented communication plan for the assessment and management of an anaphylactic allergic reaction of a child/youth at school (Food Allergy Canada, 2019).
Epinephrine	A hormone and first-line treatment for anaphylaxis that when treated promptly after allergen exposure can prevent fatal outcomes (Sicherer et al., 2018).
Epinephrine Auto-Injector (EAI)	A device that has a syringe and a needle that can administer a single dose of life-saving epinephrine. Commercial brands available in Canada include EpiPen or Allerject (Food Allergy Canada, 2019).
Epistemology	The relationship between the researcher and knowledge. The discovery of new knowledge is created through the interaction between the researcher and that which is researched (Bailey, 1997).
Food Allergy (FA)	An abnormal immune response to a food occurring when the body's immune system mistakenly interprets a food protein as harmful and causes an allergic reaction in the body (Food Allergy Canada & CSACI, 2019). An Ige-mediated FA can result in a life-threatening immune response resulting in anaphylaxis (Boyce et al., 2010). For this study, FA refers to an Ige-mediated FA or a life-threatening FA.
Food Allergy Policy	Government or school initiated documented plans of action to assist in the prevention and management of FA and anaphylaxis (Food Allergy Canada, 2019).
Hermeneutic Phenomenology	A philosophy and research methodology which seeks to understand the lived experience of a phenomenon through subjective description and interpretation (Guignon, 2012).
Ontology	Beliefs about reality (Houghton, 2012).
Parent	For this study, a parent can include the biological or adoptive mother or father or any primary caregiver of a child/or youth as defined by the family.

Lived Experience	A subjective and situated experience of a person which encompasses our perceptions, emotions, bodily sensations, social interactions, and meaning assigned to those experiences (van Manen, 1997).
Quality of Life (QoL)	Refers to a person's subjective, multidimensional appraisal of life satisfaction across emotional, physical, material well-being, relationships, and autonomy shaped by perceptions as well as cultural and value contexts (American Psychological Association, n.d.).
Relativism	A subjective approach to reality in that truth is created by meaning and experiences. Multiple realities can exist, which can be shaped by context, and can evolve over time. Truth does not exist without meaning (Killam, 2013).
Youth	For this study, a youth refers to any school-age student from age 12-19 years of age, unless otherwise specified.

Positionality Statement

I am a 50-year-old Caucasian woman living in Canada. I hold a bachelor's degree in psychology, a bachelor's and master's degree in nursing and am currently a PhD candidate at the College of Nursing in Manitoba, Canada. I am a mother of a child with a FA to peanuts and tree nuts, and this personal experience has shaped my PhD research focus. It is my belief that a research question should dictate a researcher's epistemological standpoint and subsequent methodological choices. With respect to this research, it is my view that having previous experience as a nurse and as a mother of a child with a FA has been an asset to this research study. My prior experience as a nurse helped me better understand FA from a health care perspective, while my personal experience enabled me to better understand some of the everyday realities of living with FA, both of which made it easier to notice meaningful details, ask relevant questions, and interpret participants' stories with greater depth. Because I was already familiar with this world, participants could speak more openly with a sense of shared understanding. As a novice researcher, I recognize my privilege in being able to access certain resources and have

strived to be aware of my own biases and recognize how they may have shaped my approach to this research.

Personal Reflection

As a mother of a youth with allergies to peanuts and tree nuts, many of the experiences shared by children, youth, and parents have resonated deeply with my own and those of my daughter. Van Manen (2014) purports that prior experience can be an asset within the research process and is an essential starting point for phenomenological inquiry. In this research, my prior experience was a strength as it supported the interview process where an existing understanding may have enabled me to ask more nuanced questions and allowed for deeper engagement and understanding. At the same time, I remained cognizant of the need for openness, holding my experiences reflexively so that they did not overshadow or predetermine participant accounts. It was my intent to allow meaning to emerge from participant narratives rather than from my own assumptions. Ongoing reflection documented in field notes and discussions with my advisor allowed me to maintain this stance and ensure that the findings and thematic interpretations remained grounded in participant experiences rather than my own.

In reviewing the transcripts of children as young as 8 years and as old as 16, I was impressed with the level of maturity and poise these children and youth embodied in their everyday lives, perhaps not by choice, but derived out of necessity. The depth of thought and responsibility in managing their FA safety was apparent and demonstrated through their actions. Despite some expressed fears, stress, and anxiety that was experienced along their FA journey, their resilience and strength of character co-existed through their continued commitment to safety normalized into their daily routine.

Equally striking, was extent of the invisible labour done by parents, often mothers, to create safe spaces and preserve a sense of normalcy for their child with a FA. As a parent, I can attest to the ‘behind-the-scenes’ work involved in anticipating potential issues and mitigating risks so that a child can remain safe while minimizing the impact on their ability to be included with their peers. This often involves ongoing planning, communication, and vigilance; while navigating the delicate balance of advocating for one’s child without placing undue burden on family members, teachers, or friends. From my perspective, I appreciate that not all parents have a natural ability to communicate in uncomfortable situations and in new environments, yet they do.

In reflecting on school policy, I was particularly struck by how thoughtful each participant was when thinking about the broader impact of policy on others. Even those who had nut allergies expressed a desire for policies that were inclusive to all types of FAs, while also demonstrating sensitivity to the needs of families without a FA. Throughout this inquiry, engaging deeply with participants’ narratives expanded my understanding of the varied and often multifaceted challenges families face as they navigate their journeys with FA, revealing layers of experience that extended beyond my own. These narratives prompted ongoing reflection about my assumptions and deepened my appreciation for the diverse ways families strive to create safety and inclusion for their children.

Chapter 2

Literature Review

To gain a deeper understanding of the lived experiences of children and youth with a FA, and their parents within the school environment, a thorough review of the relevant literature of what is known about FA in relation to the research purpose is first presented. This comprehensive literature review includes quantitative and qualitative research about FA as it relates to its impact on children, youth, and their parents. Three key areas are examined in the literature. First, an analysis of the literature of the impact of a life-threatening FA on children, youth, and their parents in their daily lives including overall QoL and more specifically, the impact on the physical, mental health, social, and economic impacts on the family. Next, an analysis of the literature specific to the experiences of children and youth with a life-threatening FA, and their parents within the school environment is presented. Third, Canadian legislation and recent clinical guidelines are discussed in tandem with their policy implications. While some literature in these three areas may overlap, it is the intent that the examination of each separately allows the complexities of each area to be better understood to create a comprehensive foundation of understanding of FA related experiences children, youth, and their parents.

Literature Search Strategy

A literature search was performed for the purpose of the development of this research proposal in 2022. Prior to the literature search, I consulted with a librarian at the University of Manitoba to discuss search strategies, terms, and appropriate electronic databases. A preliminary scan of the literature facilitated the identification of the key factors or key terms that were used for the formal literature search. The following electronic data bases were searched as they were recommended by the librarian and were specific and appropriate to the research questions:

Cumulated Index in Nursing and Allied Health Literature (CINHAL), EMBASE, Educational Resources Information Centre (ERIC), PubMed, and PsycINFO. A comprehensive literature search was performed using various search terms related to each concept. Slight modifications were made to meet the requirements of each data base. All concepts were combined with “OR” or “AND” to enhance the search. Some of the key terms or concepts included: *food allergy, anaphylaxis, life-threatening food allergy as it relates to its management, quality of life, anxiety, mental health stigma, bullying, social isolation, exclusion, school policy, health policy, education, student/child/youth/teen/adolescent experiences, parent/mother/father experiences, economic impact, social impact, Canadian legislation, media coverage, and COVID-19*. The electronic data base searches were followed up with title searches in key journals such as *Journal of School Nursing, Pediatric Journal of Allergy and Immunology*, and the *Journal of Allergy and Immunology*. A title search was performed on the AllerGen website in the Scientific Publications Database section. The same was done for the Food Allergy Canada website. In addition to a search for publications of peer reviewed journals, a search was conducted for relevant Master theses or Doctoral dissertations through UM MSpace, University of Toronto TSpace, Digital Commons @NLU, and ProQuest Dissertations and Theses. After eligible articles were selected, I searched through reference lists of key studies to identify primary sources or uncover research that was missed through the electronic data base searches. Finally, a literature search was conducted periodically throughout the study to ensure the research remained current, resulting in the inclusion of approximately 20 additional peer-reviewed articles and two Doctoral dissertations.

Impact of FA on Children, Youth, and Their Parents

“Food allergies can have a profound effect on a family’s life, trickling into aspects of day-to-day living both large and small” (Khamisi, 2020, p.S5). The physical impact of a FA on children and youth will be first described. Next, the impact of a FA on the overall on QoL will be addressed. QoL will then be dissected into key impacts including mental health, practical, social, and economic, so that they may be explored with greater depth.

Physical Impact of FA

FA is a complex, chronic health condition defined as an abnormal immune response to a food protein occurring when the body’s immune system mistakenly interprets a food protein as harmful (Bettcher et al., 2020). According to Food Allergy Canada, a person can be allergic to any food; however, over 90% of food allergens result from a small list of foods. These include peanuts, tree nuts, sesame, milk, eggs, fish, crustaceans and mollusks, soy, mustard, and wheat (Food Allergy Canada & CSACI, 2019). Although a diagnosis of FA can occur at anytime, it most often occurs in childhood. An estimated 85% of children will outgrow an allergy to milk, egg, soy or wheat, whereas only 15–20% will outgrow an allergy to peanuts, tree nuts, fish or shellfish (Bettcher, 2020).

Although there are two types of FA, immunoglobulin (IgE)-mediated and non-IgE-mediated, this study focused on IgE-mediated FA. An IgE-mediated FA involves an immune response that can trigger a rapid-onset allergic reaction that may result in anaphylaxis. In contrast, non-IgE-mediated allergy symptoms primarily affects the gastrointestinal system and is not associated with anaphylaxis; therefore, was not included in this study (Boyce et al., 2010). Similarly, food intolerances were not part of this inquiry. Although food intolerances can cause

symptoms of an adverse symptoms following ingestion of a food, it does not involve the immune system which can lead to anaphylaxis.

The cause of FA is not known, but research suggests that it is a mix of genetic and environmental influences which can result in an immunoglobulin E (IgE) mediated dysfunction (Sicherer, 2017). This dysfunction can trigger an intense inflammatory response to certain allergens with the onset of symptoms after exposure to an allergen varying from minutes to hours (Bettcher et al., 2020). IgE-mediated FA can result in anaphylaxis, which is defined as a severe, potentially fatal, systemic allergic reaction that can occur suddenly after contact with an allergen (Sicherer et al., 2010; Food Allergy Canada & CSACI, 2019). Symptoms of anaphylaxis most often involve two or more body systems including: cardiovascular (e.g., light-headedness, hypotension, dizziness, syncope), cutaneous (e.g., flushing, pruritus, urticaria or hives, angioedema), gastrointestinal (e.g., abdominal pain, diarrhea, nausea, vomiting), ocular/nasal (e.g., conjunctivitis, nasal congestion, sneezing), respiratory (e.g., chest tightness, coughing, wheezing, dyspnea) and may be accompanied by a feeling of impending doom (Bettcher et al., 2020). Although fatalities from a FA are rare, anaphylaxis is considered a medical emergency which requires immediate treatment with epinephrine (Sicherer & Sampson, 2018). As such, it is paramount that all persons at risk for anaphylaxis, carry an epinephrine auto-injector (EAI) such as an EpiPen which contains this life-saving medication to treat an anaphylaxis (Food Allergy Canada & CSACI, 2019).

An accurate diagnosis of a FA is important so that appropriate education and management strategies can be implemented (Peters et al., 2021). In Canada, when a FA is suspected, it is recommended that evaluation be done by an allergist to make an accurate diagnosis (Sicherer et al., 2017). However, an unfortunate reality for patients in Canada seeking

a FA diagnosis, is that depending on where they live, they may be challenged to find access to an allergist and if they do, may experience long wait times (Food Allergy Canada & CSACI, 2019).

A history of previous allergic reaction is the first step in the diagnosis of FA. It also dictates further allergen test selections such as elimination diets, skin prick testing, and serum food specific IgE bloodwork, and oral food challenges (Sicherer et al., 2017). Skin prick testing is an efficient and cost-effective way to test for FA. Skin-prick testing can be done in combination with serum food specific IgE bloodwork to measure the number of antibodies in the blood (Abrams & Sicherer, 2016). Although an oral food challenge (OFC) is considered the gold standard for a FA diagnosis, it is not used as readily as other testing because it is more expensive and time-consuming. OFC involves having the person suspected of a FA incrementally ingesting a small amount of the allergen in the presence of an allergist. Due to the inherent risks this presents, OFC are often limited to a hospital setting (Protudjer et al., 2020).

There is no cure for a FA and until recently, there have been no treatments that reduce the impacts of FA (Sicherer et al., 2017). Allergen avoidance, education, and access to treatment for anaphylaxis (i.e., epinephrine) remain the primary management strategies. Oral immunotherapy (OIT) and sublingual immunotherapy (SLIT) are emerging treatments for FA; however, access to these options remains limited throughout Canada (Food Allergy Canada, 2025). The focus of OIT and SLIT is to give increasingly tiny amounts of a food allergen under medical supervision until a maintenance dose is determined (Bettcher et al., 2020). The goal of treatment is to gradually desensitize people so that they may tolerate a small amount of their allergen with the intent of improving QoL. Despite these emerging therapies for FA, the gold standard of care continues to focus on strict avoidance of the known allergen and prompt treatment of symptoms with epinephrine should exposure occur (Sicherer et al., 2017).

FA has become one of the most common chronic conditions diagnosed in children; however, it is unique when compared to other chronic health issues in that children and youth with a FA are otherwise physically healthy day-to-day (Herbert et al., 2016). Unlike other chronic issues, there is a constant, unpredictable, and invisible threat of a life-threatening allergic reaction from an accidental exposure and the burden of constant vigilance to minimize this risk rests primarily with families (Food Allergy Canada, 2020). All family members impacted by FA must live with the uncertainty, risk, and are thrust into steep learning curve about FA management (Dunn Galvin & Hourihane, 2016).

Overall Impact of FA on QoL

Much research has focused on the impact of FA on QoL, in recognition that it is an important outcome measure in children and youth with a FA, and their parents (Dunn Galvin & Hourihane, 2016). The World Health Organization (WHO) defines QoL as “the individual’s perception of their position in life in context of the culture and value systems in which they live and in their relation to their goals, expectations, standards, and concerns” (WHO, 1948). Further, health-related QoL is defined as the patient’s perception of their health and how they feel (Patrick & Bergner, 1990). Dunn Galvin and Hourihane extend this definition as “a multi-dimensional construct that evaluates physical, psychosocial, and social components that may be impacted by a disease or condition, from a patient perspective” (p. 841).

There are two types of health-related QoL measurement tools, generic and disease specific (Dunn Galvin & Hourihane, 2016). Generic QoL instruments allow comparisons across conditions as they are broad in focus, whereas disease-focused instruments concentrate on concerns to the specific disease (Greenhawt, 2014). According to Dunn Galvin and Hourihane, disease specific tools allow for an in-depth understanding of issues relevant to daily life and can

capture small changes that may occur because of a change in daily life or medical intervention. The shift from general to FA specific QoL measures can be attributed, in part, to the qualitative research studies exploring the experiences of families providing a better understanding of FA's specific impacts (Moen et al., 2019).

The goal of FA QoL tools is to improve screening and support timely referrals for those who would benefit from additional supports to reduce the burden of FA. Emotional, dietary, social, and economic burdens are the key impacts on QoL expressed by children and teens with a FA and their families (Dunn Galvin & Hourihane, 2016; Greenhawt, 2014; Moen et al., 2019; Ravid et al., 2012; Walkner et al., 2015). According to Greenhawt, because children and youth with a FA are generally physically healthy day-to-day, assessing the impact of physical symptoms as part of overall QoL in FA is not warranted. Some of the most common food allergy QoL questionnaires include: *Food Allergy Quality of Life Questionnaires (FAQLQ)* for children ages 8-12 years (Flokstra-deBlok et al., 2009a), teens ages 13-17 years (Flokstra-deBlok et al., 2008), and parents (Flokstra-deBlok et al., 2009b), *Food Allergy Parent Questionnaire* (LeBovidge et al., 2006), *Food Allergy Quality of Life Parental Burden Scale* (Cohen et al., 2004), *Food Allergy Quality of Life – Parent Form* (Dunn Galvin et al., 2008), the *Paediatric Food Allergy Quality of Life Questionnaire* (Knibb et al., 2013), *Food Allergy Independent Measure* (van der Velde et al., 2010), *Food Allergy Self-Efficacy Scale for Parents* (Knibb et al., 2015), *Food-Allergy Self-Efficacy Questionnaire* (Greenhawt & Dunn Galvin, 2018), and the *Scale of Psychosocial Factors in Food Allergy* (Cortes et al., 2013). Further, the *Economic Costs of Food Allergy Questionnaire* seeks to measure the economic burdens of FA (Fox et al., 2009), while the *Social Activity Limitations Inventory* (Peterson & Harrison, 2018) focuses on the social impacts on QoL. According to Antolin-Amerigo and colleagues' (2016) review of FA-related QoL

literature, the *Food Allergy Quality of Life Questionnaire (FAQLQ)* is the most used QoL instrument in children, youth, and parents.

FA is negatively associated with health-related quality of life (HRQL) for children and youth with FA, and their parents. Mothers report poorer HRLQ than do their child with a FA (Protudjer et al., 2021). Parents believe that their school-aged children with a FA (ages 7–12), have worse QoL related to their allergy than their younger children with no FA (Wassenberg et al., 2012). Poorer health related QoL in mothers has been attributed to an increased risk perception of accidental exposure to a food allergen when away from home. Similarly, Thornqvist and colleagues reported that children between the ages of six to 12, have worse QoL when compared to children less than five years of age with a FA (2019). These authors suggest that this may reflect that by age six, children with a FA can recognize and internalize the demands and stressors associated with a FA (Thornqvist et al., 2019). Results from Miller et al.’s study (2020) using the Food Allergy Quality of Life Questionnaire completed by youth (ages 13–17) and parents for children (ages 0–12) revealed that youth were affected by their FA more than children in all areas of their daily lives (emotional, dietary, and social). Golding and colleagues’ (2021) systematic review results also demonstrated reduced quality of life in children and teens with a FA, especially in older children and those with severe or multiple FAs.

Overall, some research suggests that the impact of a FA on QoL is greatest at time of diagnosis and at times of transition (i.e., starting school) and has a more minimal impact over time as families adapt to a new normal (Cummings et al., 2010; Roy & Roberts, 2011). Valentine and Knibb (2011) found that the impact of a FA on QoL was greater in parents than their school-aged child with FA. For parents, social negativity was a stronger predictor of HRQL than not having social support (Williams & Hankey, 2015). In other words, the negative impacts on

parents socially, outweigh the benefits of having strong social support networks. For children, fear of an allergic reaction, fear of bullying, and social exclusion impacted their overall QoL (Moen et al., 2019). Parents described stress and anxiety when their child was out of reach while at school (Lagercrantz et al., 2017) and the need to let go of control for their teenagers as they begin to experience more freedom and expanded social worlds (Gallagher et al., 2012). For youth (over age 12), the negative impact on their quality of life was tied to their social lives and learning to navigate the risk and responsibility of their allergy independently (Dunn Galvin & Hourihane, 2016; Johnson & Woodgate, 2017). Teens with a FA who attend social events need to take additional precautions (e.g., bringing their own food or carrying an EAI) which can be a source of embarrassment. Consequently, teens may be more likely to take risks such as failing to disclose their food allergy in social settings or not always having their EAI with them (Golding et al., 2022).

Research about children and youth with a FA, and their parents which is grounded with a theoretical foundation or conceptual framework is limited. Moen et al. (2019) noted in their qualitative review of parent experiences of raising a child with a FA, that although the articles included in the review were assessed to be of high quality, only 26% of these studies acknowledged the philosophical underpinning of their chosen research methods. The inclusion of theory and philosophical underpinnings in research is important to ensure the strength and continuity of the research design and thus, strengthening confidence in the results (Dunn Galvin et al., 2020). Additionally, theories or conceptual frameworks provide a roadmap to guide and interpret research. The absence of an explanatory framework guiding research may limit the ability of researchers, health care providers, and policy makers to understand, predict, and evaluate the impacts of FA (Dunn Galvin et al., 2009).

In 2009, Dunn Galvin and colleagues were the first to develop a conceptual framework of developmental pathways of children with a FA using grounded theory methodology. This conceptual framework demonstrates the developmental growth children go through and how it impacts their understanding and ability to cope with their FA. Building off this work, Dunn Galvin et al. (2020) developed two more conceptual frameworks; one that illustrates the impact of allergy and coping strategies on children and teenagers with a peanut allergy and the other used to illustrate these impacts on caregivers. These frameworks are complex in nature; however, they conceptualize the relationship of the main factors for coping and control (e.g., daily vigilance, communication, and practical) and their potential impacts (e.g., school/work, relationships, emotions). Dunn Galvin and colleagues also added factors such as social attitudes, support, coping strategies, and relationships that can moderate these impacts. This most recent work provides a detailed framework to guide one's understanding of the impacts of a peanut allergy on QoL and is a useful framework to guide future research in this area.

Mental Health Impact of FA

The lives of children and youth, and their parents are impacted by FA and the constant vigilance required to maintain safety can take a toll on the mental health of the entire family (Moen et al., 2019). Over the last twenty years, there have been many research inquiries about the mental health impact of FA, with varying foci on anxiety, worry, depression, psychological distress, and psychosocial impact (Procter et al., 2021). These quantitative and qualitative studies have wide variation in their focus and methodology and further, often lack conceptual clarity, and a theoretical framework (Polloni & Muraro, 2020). This variability and conceptual blurring make generalizations about anxiety and other mental health impacts related to FA more

challenging. Despite these limitations, existing research on the emotional impacts of living with a FA has contributed to our current and evolving understanding.

Anxiety arising from caring for someone with a FA is a significant mental health concern which can impact overall QoL (Gallagher et al., 2012). Historically, anxiety due to FA has not been conceptually explored in the literature and was most often defined by the assessment tool used by the researcher and/or it was tethered to QoL results (Polloni & Muraro, 2020). In earlier research, generalized anxiety and depression scales such as the *Hospital Anxiety and Depression Scale* (Zigmond & Snaith, 1983) or the *STAI Scale* (Spielberger et al., 1983) were used to assess anxiety and depression in children, youth, and parents (Polloni & Muraro, 2020). Findings from studies using generalized anxiety and depression tools should be interpreted with caution, as these measures are designed to detect clinically diagnosable disorders that may not adequately capture FA experiences that may fall below a clinical threshold (Poehacker et al., 2021).

Soller and colleagues (2020) analyzed both general anxiety scales and FA specific QoL tools with anxiety subdomains and determined that these instruments failed to capture anxiety specific to FA. With this in mind, a 13-item *Worry About Food* questionnaire for assessing parental anxiety in pediatric FA was developed and showed promise as a valid and reliable screening tool (Poehacker et al., 2021). Similarly, Dahlsgaard et al. (2022) developed child and parent rated scales of FA anxiety which may be useful screening tools for use in clinical practice.

The experience of anxiety in children and youth with a FA, and their parents is variable. According to Ciaccio and colleagues (2024), FA specific anxiety varies by person and for each person among people with more than one FA. Higher anxiety was reported in parents of a child with FA when compared to parents of healthy children (Cortes et al., 2013) and parents of children with other chronic illnesses (Knibb, 2013). No differences in anxiety or depression were

noted in parents of a child with a FA when compared to parents of a child with an orthopedic injury (Ogg et al., 2017) or parents of child with a food hypersensitivity (Burke & Hooper, 2017). Fedele (2016) examined the relationship between FA management and anxiety and found that although 45% of parents and children with FA had adequate FA management, high levels of anxiety were reported. In Sanagavarapu's (2016) study, mothers reported heightened feelings of anxiety when their FA child transitioned to school. Mothers reported significantly more anxiety, stress, and poorer physical health than fathers, siblings, and child with a FA in a QoL study by King et al. (2009). Caner and colleagues (2023) described the psychological burden of caring for a child with FA as a constant worry and anxiety about their child's safety. Elevated levels of maternal anxiety have also been reported and its negative impact on their child's anxiety and overall QoL (Goodwin et al., 2017; Manassis, 2012; Moen et al., 2019). According to Stensgaard et al. (2017), adolescents with a FA, siblings, and the fathers regarded the mother as the primary resource for FA management. Acting as a primary resource for FA within the family may contribute to higher levels of anxiety that has been described by mothers.

The recent work by Westwell-Roper et al. (2021), provides conceptual clarity on food allergy anxiety (FAA) in parents and will shape future research in standardizing clinical care and assessment. FAA is conceptualized using a cognitive behavioural framework and includes affective dimensions (i.e., fear, hypervigilance, hyperarousal), cognitive dimensions (i.e., worry about general health, uncertainty of risk of allergen exposure, management of emergencies, social issues) and behavioural dimensions (i.e., limitations and avoidance of social situations; isolation). According to this study, FAA was associated with the perception of increased risk, expectation of negative outcomes, and an intolerance of uncertainty. A similar conceptual

analysis is required for children and youth, so that future research and clinical interventions will be more attuned to the nuances of FAA in these age cohorts.

Anxiety, fear, and worry are common issues for children and youth with a FA. Although anxiety related to FA may not always meet the clinical threshold of generalized anxiety disorder, feelings of worry and social and/or separation anxiety are commonplace (Dunn Galvin et al., 2009; Petrovic-Dovat, 2016; Polloni & Muraro, 2019). Children with a FA can have many fears impacting their QoL including fear of exposure to their allergen, anaphylaxis and death, needles, eating outside the home, travelling, and exclusion from their peers (Goodwin et al., 2017; Howe et al., 2014; LeBovidge et al., 2009). Dunn Galvin et al. reported that after eight years of age, children become more aware of risks and safety concerns related to FA management and at this time anxiety may begin to elevate. It has been postulated that a moderate amount of anxiety related to FA may be helpful as it promotes vigilance and is indicative of high compliance with avoidance of a food allergen (Mandell et al., 2005; Polloni & Muraro, 2020). In 2005, Mandell and colleagues, referred to this as the “Goldilocks’ principle”; that is, to find the optimal level of anxiety that facilitates FA related coping. This concept is still mentioned in Polloni & Muraro’s review in 2020 as a recommendation for future studies to clarify “just the right degree of anxiety” required to manage their FA. To suggest that clinicians should encourage families to find the right amount of anxiety is troubling as it risks normalizing distress as necessary for safety, rather the emphasis may be more appropriately focused on education or other therapeutic interventions such as cognitive behaviour therapy that seeks to promote self-efficacy and healthy coping strategies as articulated by Westwell-Roper and colleagues (2021).

Although there are conflicting reports in the literature, it has been suggested that the psychological burdens of a FA may have greatest impact on youth. According to Quach and John

(2018), adolescents are four times more likely to develop psychosocial issues such as depression or anxiety because of their FA than adolescents without a FA. Fox and Warner (2017) measured social anxiety in adolescents (ages 13–17) with a FA and found that FA was not associated with social anxiety. Given the study's focus on social anxiety, anxiety from other sources such as EAI use, allergic reactions, death, food choices were not captured. In another study, Ferro et al. (2016) examined the associations of FA with depression and anxiety in youth (ages 14–21), found that FA was not associated with depression, but was associated with anxiety. In contrast, Dunn Galvin and Hourihane (2016) state that social restriction as a result of their FA leaves youth at greater risk for depressive symptoms. These conflicting findings highlight the need to better understand the psychological burdens youth with a FA may experience.

Practical and Social Impact of FA

A diagnosis of FA presents several challenges for families in their daily life (Abrams et al., 2020). After a FA diagnosis, parents describe a shift in their lifestyle such as learning to read food labels, adapt their meal preparation, and adjusting their social interactions (Agnihotri et al., 2019; Caner et al., 2023; Chooniedass et al., 2020). Many families with a child that has a FA describe feeling safest at home and exert incredible effort in careful meal preparation and planning to minimize the fear about accidental allergic reaction both inside and outside the home (Moen et al., 2019). Families spend considerable time educating extended family members, friends, and community members with whom they interact on FA safety and management (Hurst et al., 2021). Despite this education, going over for dinner at a friend or family member's house can still be stressful for fear of cross-contamination of food and accidental exposure. As a result, some families with a FA frequently opt to host social events to minimize these risks and offset vigilance fatigue (Hurst et al., 2021). Some families affected by a FA describe feeling

overwhelmed and alone, particularly if there was a lack of support from extended family or their inner social circle (Abrams et al., 2020).

Families of children with a FA have described limiting or avoiding social events outside the home due to the anxiety, fear, and effort required to maintain safety (Caner et al., 2023; Ciaccio et al., 2024). Given these stressors, social events such as sporting games, birthday parties, cinemas, playdates, and dining out are sometimes avoided to reduce the risk of exposure to unsafe foods (Dunn Galvin et al., 2020; Lieberman et al., 2021). It has been reported that some parents do not allow their child with a FA to attend events outside the home or school without a parent present. This level of vigilance can lead to perceptions of parents as being paranoid, neurotic, or difficult and results in children missing out on valuable life experiences (Sanagavarapu, 2004). According to Dunn Galvin and colleagues, children and youth describe the disappointment of being not being able to share food with others and being excluded and/or having to miss social events such as birthday parties and camp. Approximately 25% of caregivers in this study reported avoiding social events entirely if they felt they could not control the environment to protect their child (Dunn Galvin et al., 2020). According to a study by Dyer and colleagues (2020), for those families who choose to attend social gatherings, almost half brought their child their own food as a precautionary measure.

A child's development and age are important considerations when looking at the practical and social impacts of FA. Younger children rely on their parents for safety, control, and management; while older children and youth have growing social worlds and begin to take greater responsibility and risk management for their allergy (Dunn Galvin & Hourihane, 2016; Gallagher et al., 2012). Adolescence represents a period of increased self-reliance as they take on more responsibility for their allergy at school, in the community, and within their social

environments (Johnson & Woodgate, 2017). Johnston and Woodgate report that youth begin to handle social situations by advocating for themselves through clear communication, engaging in safe decision-making and recognizing the need for vigilance to minimize risk and maintain safety. This increasing responsibility can be challenging in this stage as they can be influenced by their peers and can make impulsive decisions. Teens may take risks such as not always carrying their EAI or failing to disclose their FA in a social setting for fear of embarrassment or exclusion (Golding et al., 2022; Stjerna, 2015). Eating out in restaurants with friends is important in their growing social life, but this activity is also a challenge that can limit their ability to join their peers in certain social settings. Teens felt more secure in social environments when they were with friends who knew them well and were aware of their FA (Stensgaard et al., 2016).

Parents with a child with a FA are challenged to balance the need to establish safe environments with empowering their child to fully participate in their lives, resulting in a constant negotiation of relationships and managing risk (Ciaccio et al., 2024; Dyer et al., 2020; Lagercrantz et al., 2017). FA impacts family dynamics and can create strain and conflicts amongst family members (Chooniedass et al., 2020; Williams & Hankey, 2015). Almost 25% of caregivers indicated that their child's FA had a negative impact on their relationship with their partner. These researchers reported negative impacts within the family such as arguing over increased supervision, remembering the EAI, and differing perspectives on how best to manage FA (2020). According to Walkner and colleagues (2015), parents perceived managing their child's FA had a negative impact on their own friendships as they often needed to ask for accommodations for their child's allergy.

While research has largely focused on the experiences of parents and children living with FA, siblings remain comparatively underexplored, with only limited emerging evidence offering

some insight. Siblings, especially older, are often overprotective of their sibling with a FA. Many learn about FA management and take an active role in keeping a safe environment for sibling (Stensgaard et al., 2016). Frequently, they adopt the same diet as their sibling with a FA (Agnihotri et al., 2019). Siblings have also expressed feelings of anxiety about FA emergencies and its potentially fatal implications for their brother or sister with a FA (Stensgaard, et al., 2016).

Economic Impact of FA

The psychosocial impacts of FA on children and parents have been generally well described in the literature, while knowledge about the economic impact of FA is still emerging. FA is associated with direct, indirect, and intangible costs to the family (Caner et al., 2023; Frykas et al., 2021; Protudjer et al., 2025). In a systematic review conducted by Bilaver and colleagues (2019), these researchers noted that economic burden of FA was measured in different ways in the studies reviewed, making direct comparisons on a global level difficult to ascertain. In the US, direct medical costs from childhood FA which include medical appointments, emergency department visits, and inpatient care is estimated to be \$4.3 billion per annum (Fu et al., 2017; Lieberman et al., 2021). A European study conducted by Fox (2013), found that costs of health care were twice as high among children with severe allergies when compared to children with a mild FA. In a Canadian study by Cardwell and colleagues (2022), the economic burden was greatest among those who experience severe FA's, multiple FA's, and those in poor general health. Further, with the emergence of new therapies such as OIT and SLIT in the management of FA, the high costs associated with this treatment may make this out of reach for many families (Protudjer et al., 2025). In another recently published scoping review on the economic impacts of FA, Fong et al. (2022) highlighted the various burdens such as

household costs (e.g., EAIs, allergen free foods), health care costs (e.g., early allergen introduction and screening, specialist care, emergency department visits), and food industry concerns (e.g., labelling).

Families affected by a FA often incur a significant financial burden (Cardwell et al., 2022). In Canada, there are no specific tax benefits offered to families living with a person with a FA (Government of Canada, 2022). Estimated costs covered by families such as out-of-pocket expenses, lost labour productivity of parents and caregivers, and job opportunity costs was calculated to be about \$20.5 billion USD per annum (Gupta et al., 2013). Allergen free foods and changes to childcare or schooling are recognized as the largest out-of-pocket expenses (Bilaver et al., 2019). A cross-sectional study based in Winnipeg, Canada, estimated that families with children with a FA spent approximately \$2300 CAD more per year for out-of-pocket expenses when compared with controls (Golding et al., 2021).

FA is associated with many indirect or intangible costs to the family some of which may be difficult to quantify or calculate. Lost labour costs to families are calculations based on unearned wages due to parent or caregiver time spent on health care visits (Gupta et al., 2013; Hurst et al., 2021). According to Bilaver et al. (2019), lost labour estimates were \$1038 USD per family and opportunity cost estimates were calculated at \$4881 USD. According to Gupta et al. job opportunity costs were defined as costs to families because of having to restrict career choice or change, leave, or lose a job due a child's FA. A recent Canadian study examined the impact of a FA on their career of parents and although no fathers reported career limitations, 14.3 % of mothers interviewed reported career limitations due to their child's allergy (Frykas et al., 2021). Further, mothers of a child with multiple FAs reported worse perceived life status than mothers of a child with less than two allergies (Frykas et al., 2021). Finally, costs associated with mental

health supports for children or family have yet to be estimated and as such, should be included in future research given the frequent quality of life related burdens cited in the literature.

Socioeconomically disadvantaged families that have a child with a FA face even greater financial burden (Cardwell et al., 2022) and may have poorer access to anaphylaxis treatment (Hurst et al., 2021). Although, extended health care coverage or social assistance often cover the cost of an EAI, some families lack awareness of coverage or do not have any coverage and have to pay over \$100 CAD per EAI (Minaker et al., 2014). Due to the high costs, a family may opt for keeping expired EAIs or having none (Minaker et al., 2014, 2015; Hurst et al., 2021). Some families have also stated that they have purchased antihistamines to treat allergic reactions, which is not a recommended, because they are more affordable (Minaker et al., 2014). Access and affordability of allergen safe food is an issue for all families with a FA (Chooniedass et al., 2018), but an issue that impacts lower income families disproportionately. Some low-income families revealed that declaring a FA at a food bank can result in getting less food rather than being substituted with a safe option and others describe having to shop at discount markets with less product availability (Minaker et al., 2014). Protudjer et al. (2025) emphasized the need for greater availability of lower cost foods at food banks and discount food stores.

Impact of Support and Intervention on Families Affected by FA

Stakeholders, including families with a FA, have identified reducing the psychosocial impact of FA as a patient-centered research priority (Proctor et al., 2021). FA screening tools described in the previous section, should be incorporated to all points of contact of families of FA and their health care providers (e.g., FA clinic) so that those who would benefit from an intervention would be identified and referred (Quach & John, 2018). Psycho-educational interventions for caregivers and children or youth with a FA are targeted at increasing education

to promote coping and adaption to FA (e.g., Food Allergy Canada newsletters, webinars), psychological interventions (e.g., cognitive behavioural therapy) to improve anxiety, and peer or professional support groups to help lessen the burdens of FA (Herbert et al., 2016; Knibb et al., 2024; Marsac & Wurth, 2021; Stewart et al., 2011). In Knibb and colleagues' systematic review, these researchers highlight the potential benefits of cognitive-based interventions for anxious parents and children. Although more research is needed, free online support programs are an emerging intervention that may be helpful to both children, youth, and parents in dealing with a FA (Knibb et al. 2024; Sugunasingha et al., 2020; Vreeken et al., 2021).

Impact of FA within the School Environment

Starting school is supposed to be an exciting time; however, for families affected by a FA, the transition to school can be fraught with worry about safety and well-being of their child (Sanagavarapu, 2016, 2018). According to *Bronfenbrenner's Socio-Ecological Theory* (1977, 1979), a child's successful transition to school is contingent on the positive relationships between parents, teachers, and peers (i.e., microsystems) and the mesosystems of home, school, and community (See Appendix C). Before children begin school, parents are primarily responsible for managing their child's FA. With the onset of school, this responsibility shifts as parents must establish relationships with teachers and begin to trust the school community for their child's safety (Sanagavarapu, 2018). In this heightened period of anxiety, parents must also learn about school policies (i.e., exosystem) and work with schools and/or public health to ensure emergency plans are in place (Sanagavarapu, 2016). As a child becomes of school-age, there is there is increasing awareness of their FA and as they develop more independence, they begin to take a more active role in management of their FA (Quach & John, 2019). Children and youth spend the most of time during weekdays in school, so allergic reactions can and do occur within this

setting (Lawlis et al., 2017; Rubiez & Ernst, 2021). Lunch and snack time can leave the child or youth at risk for accidental exposure to a food allergen and teachers' and students' lack of awareness further contributes to a child's risk (Feldman et al., 2022). Although accurate reports are difficult to ascertain, Wasserman et al. (2021) estimate that there are 1.3 allergic reactions for every 350 students every year, while Wang et al. (2017) estimate about 40% of schools reported an allergic reaction within the past 2 years. Sanagavarapu (2020) found that 16% children with a FA had at least one allergic reaction at school during non-routine activities. Further, it is estimated that anaphylaxis occurs in about 1 in 15 schools and 1 in 24 schools administer epinephrine every year (Wasserman et al., 2021).

Youth with a FA pose the highest risk for adverse reactions, including death due to anaphylaxis (Bock et al. 2001, 2007). Youth are entering a stage of peer-approval seeking, impulsivity, and risk-taking (Gupta, 2014; Mustafa & Bess, 2018; Sampson et al., 2006) at a time when Dupuis et al. (2020) reported that youth and their parents felt school policies became less enforced and more ambiguous during these life stages. Youth with a FA can have variable levels of allergy education and confidence about self management and can exhibit fear and anxiety about potential reactions at school (Sanagavarapu, 2016). Additionally, knowledge and experience about FAs can vary with other students, teachers, and staff in schools (Ercan et al. 2012; Feldman et al.; Wasserman et al., 2021).

As younger children transition away from their controlled home environment and older youth are gaining more independence about allergy management, consideration of the factors surrounding FA management at school is not only important for the safety of children and youth with a FA, but to ensure they have the same opportunities to thrive as their non-FA peers. Results of QoL study measuring the impact of FA on QoL for female and male children (ages 8-

12) revealed poorer QoL scores when compared to their healthy siblings and girls had poorer QoL scores than boys (King et al., 2009). Golding et al. (2021) report that older children are impacted more negatively than their younger counterparts. Effective FA allergy management plans in schools should include evidence-based FA policy, stock epinephrine, emergency care plans for students with FA, staff training about prevention, recognition, treatment of allergic reactions, and strategies to minimize the psychosocial impacts (Greenhawt et al., 2020; Heideman & Poronsky, 2021; Quach & John, 2018; Wasserman et al., 2021). The following discussion touches on the current literature in the aforementioned areas.

Impact of FA Policy in Schools

One of the most important factors influencing the experiences of FA within the school environment is FA legislation and policy. In 2003, a 13-year-old student from Ontario, Sabrina Shannon, died from cross-contamination of food in her school cafeteria resulting a fatal allergic reaction (Dean et al., 2016). In response, the Government of Ontario passed legislation in 2005, *Sabrina's Law*, requiring all school boards in Ontario to implement an anaphylaxis policy that includes prevention and management of FA (Dean et al., 2016; Feldman et al., 2022; Murdoch et al., 2018; Ontario Laws, 2005). Since this time, similar legislation or provincially mandated policy has been enacted across Canada (Food Allergy Canada, 2021). It is important to note that while provincial legislation establishes the legal requirements, these are operationalized through school board policies and implemented locally in schools. While national recommendations and guidelines are available to inform policy, there is no legal requirement for these to be followed, nor do they provide guidance on how compliance with requirements should be assessed (Santos, 2022). It is therefore not surprising that a lack of standardized school policies around FA and anaphylaxis is still being reported in Canadian and US schools (Cicutto et al., 2017; Dean et al.

2016; Dupuis et al., 2020; Egan & Sicherer, 2016; Fenton et al., 2013; Greenhawt et al., 2020; Lawlis et al., 2017; Murdoch et al. 2018; Raptis et al., 2020; Rocheleau & Rocheleau, 2020; Sanagavarapu, 2018; Shahzad Mustafa et al., 2018). Three key policy issues which impact both the student with FA and their families are discussed below.

Epinephrine in School. Currently, there remains wide variability in the availability, accessibility, and carriage of EAIs in Canadian schools (Ben-Shoshan et al., 2008; Quill et al., 2025; Shah et al., 2014). Despite expert recommendations that individuals with a FA self-carry epinephrine, this is not a universal requirement across Canada (Waserman et al., 2021). Another recommendation is to have unassigned or stock epinephrine (e.g., EAIs) in schools nationwide. There is consensus in all studies from FA experts, school staff, and parents that stock or unassigned epinephrine should be required in schools and should be reflected in provincial and/or national health policy (Abrams et al., 2020; Behrmann, 2010; Greenhawt et al., 2020; Raptis et al., 2020; Waserman et al., 2021). Although the Government of Alberta's Bill 201 mandates a minimum of one EAI per school, this is not universal across Canada (Statutes of Alberta, 2019). Given that 25% of students are estimated to experience anaphylaxis for the first time in school with no history of FA, this is essential (Food Allergy Canada, 2024; Sicherer, 2010; White, 2016). In a study examining parent identified issues about FA, Canadian parents not only recommended a national policy about stock epinephrine for schools, but also a policy to offset the cost of epinephrine for families (Abrams et al., 2020).

Policy for Use of National Guidelines. Another recurrent theme in the literature about FA and schools was a need for federal legislation or a national policy mandating the use of existing national guidelines on FA prevention and anaphylaxis treatment in schools to increase student safety and decrease variability across school districts (Abrams et al., 2020; Cicutto et al.,

2011; Sanagavarapu, 2018). Although Food Allergy Canada (2020) has published guidelines and recommendations for schools in Canada, frustration exists because its use is not legally required; therefore, national guidelines have not been universally implemented. As a result, concern has been articulated from both school staff and families about the variability in FA management in schools (Abrams et al., 2020; Eastwood & Cutter, 2010; Ercan et al., 2012; Feldman et al., 2022; Lawlis et al., 2017; Nieto-Eugenio et al., 2020; Polloni et al., 2013; Sanagavarapu, 2018; Santos et al., 2022). Variability in policy can result in different approaches to accommodate children with a FA in schools such as food bans versus an allergen free table or the location and availability EAIIs (Cicutto et al., 2017; Raptis et al., 2020; Sanagavarapu, 2020; Stjerna, 2015). In Canada, parents in a legislated school environment that used national guidelines felt more supported, less stressed and anxious when compared to parents in non-legislated environments that used school developed FA guidelines (Cicutto et al., 2011; Elliot et al., 2015).

Food Ban Policies. The third theme is the most contentious as it relates to the policy debate about whether schools should implement school wide food bans (i.e., nut-free schools). Uncertainty among parents, schools, and policymakers still exists in Canada about how best to approach FA management in schools, in part, due to the aforementioned variability in school policy, legal implications, and concerns for safety (Murdoch et al., 2018; Santos et al., 2022). Debate continues about how best to balance the needs of children with a FA with the needs of the wider school population (Stjerna, 2015). Most Canadian schools have policies in place to accommodate FA ranging from school wide food bans, nut-free classrooms, or designated nut-free tables (Murdoch et al., 2018). According to expert consensus recommendations, school policy should shift away from food bans and focus on no food sharing, handwashing before and after meals, and cleaning surfaces with detergent before and after use (Greenhawt et al., 2020;

Waserman et al., 2021, 2022). These most recent recommendations represent a major shift in the discourse in the Canadian landscape and will be further explored later.

Impact of FA Education and Awareness

School teachers are the primary caregivers responsible for providing a safe and health learning environment for students, including those with a FA. A lack of education about FAs and training in anaphylaxis identification and management by the school have been identified as factors within the school environment that can put school-aged children at risk and impact their QoL (Abrams et al., 2020; Dupuis et al., 2020; Eastwood & Cutter-Mackenzie, 2010; Ercan et al., 2012; Raptis et al., 2020; Sanagavarapu, 2020; Santos et al. 2022, 2023). Lack of awareness can range from general knowledge about FAs to a lack of knowledge about local policies, emergency action plans, and anaphylaxis training (Dupuis et al., 2020; Ercan et al., 2012; Cicutto et al., 2011; Santos et al., 2022). Dupuis and colleagues reported that a lack of awareness of FA by teachers and staff was associated with reduced empathy from teachers and families without a FA. In England, Raptis et al. reported that in England, primary schools did not meet safety standards as recommended by international organizations. Less than half of teachers surveyed felt confident to manage a student experiencing anaphylaxis and an overwhelming 81% of schools surveyed believe that further education and training about FA safety and management is warranted. A Canadian study that examined EpiPen administration technique, assessed that over 80% of school staff had suboptimal technique (Cicutto et al., 2012). Further, in a Canadian scoping review (Santos et al., 2022), wide variability in teacher knowledge about FA, its management, and training was reported. In Turkey, knowledge gaps are even more alarming with only 10% of primary teachers having knowledge about epinephrine, with even fewer (4%) knowing where the EAI injection should occur (Ercan et al., 2012).

Mandatory, standardized training for EAI and emergency action plans (EAPs) to improve school staff preparedness has been recommended based on the results of a recent scoping review (Santos et al., 2022). Although annual anaphylaxis training of all school staff has been identified as important, some believe this goes well beyond the scope of a teacher's responsibility (Greenhawt et al., 2020). Primary school teachers from Australia felt the anxiety and stress of having the added responsibility of having to prevent and respond to a life-threatening allergic reaction and believed that this responsibility went beyond their responsibility as an educator (Eastwood & Cutter-Mackenzie, 2010). As such, parents of children with a FA expressed worry and concern because some teachers did not want to take on the additional responsibility of FA prevention or administration of an EAI (Nieto-Eugenio et al., 2020). This raises the question of whose responsibility is it to keep children safe within the school environment.

In countries like the US, school nurses take on the responsibility of ensuring action plans are in place, advocating for stock epinephrine, and increasing FA education and EAI training in the school community (Robinson & Ficca, 2012). Simeone and colleagues (2025) highlighted the valuable role of school nurses in FA management including implementing health plans and EAPs, ensuring timely administration of epinephrine, and engaging in psychosocial interventions targeted at reducing stigma, bullying, and anxiety. Tsuang & Wang (2016) recommend increasing the number of onsite school nurses to help address FA in schools. Although school nurses are ideally suited to manage FAs, the presence of a full-time school nurse is not a reality for the majority of Canadian schools (Buduhan & Woodgate, 2021). Without a school nurse, the weight of responsibility falls onto teachers to implement prevention strategies, assess for allergic reaction, and give epinephrine as per their assessment (Efthymiou et al., 2021; Kao et al., 2018).

Given existing teaching responsibilities and recognizing that FA is only one of many health concerns present in schools, adding these duties to educators is neither sustainable nor safe in the long term. Reintroducing on-site school nurses in Canadian schools warrants reconsideration as an investment in student and staff safety and well-being.

Stigma and Social Isolation

Stigma and social exclusion because of FA can lead to isolation and can increase the risk for teasing and/or bullying (Behrmann, 2010; Lieberman et al., 2010). Stigma is a socially constructed co-occurrence of labeling, stereotyping, separation, and discrimination of a person or groups (Minaker et al., 2015). Allergy-related stigma, social exclusion, and isolation are often cited as factors within the school environment that can negatively impact children and youth with a FA; however, there remains a dearth of research that examine these issues in any great depth. A study by Dean et al. (2016) appears to be the exception, with its focus on social stigma as an unintended consequence of Sabrina's Law developed to protect children and youth with a FA.

According to Dean and colleagues (2016), school policies meant to keep students with a FA safe can unintentionally result in practices that leave them feeling stigmatized, excluded, and isolated. Some examples of these unintended consequences include posting pictures of the FA child visible to others, segregating children with a FA to sit at a designated allergy table at lunchtime away from their peers and not being fully able to participate in school crafts, field trips, or class celebrations (Dean et al., 2016; Dupuis et al., 2020; Sanagavarapu, 2020; Stjerna, 2015). All of these examples of exclusion send strong messages to the child and youth with a FA that they are different and labelled as 'other' in their community (Dean et al., 2016; Stockhammer et al., 2021). Similarly, all children with a FA in Fenton et al.'s (2013) study described examples of social exclusion at school by being left out of classroom activities, being deprived of time

with friends, or being singled out for their FA. According to one study participant reflecting on their experience at school, “Food, everybody loves food, it brings everybody together. But at the time, it didn’t bring me together; it kind of pushed me away. I just did not enjoy the social situations with food involved” (Anderson et al., 2021, p.3). Children self-carrying an EAI on person is a visible marker that easily identifies them as different and can be stigmatizing which can impair their sense of belonging (Fenton, et al., 2013; Gillespie et al., 2007; Minaker et al., 2015). Stigma and social exclusion can lead to isolation and increases the risk for teasing and/or bullying (Behrmann; Lieberman et al., 2010). Students with a FA want to participate in the normal routines of school life as it is important to their sense of belonging to the school community (Fenton et al., 2011, 2013). Schools have an obligation to ensure that each student, regardless of their age, social or medical background, feel safe, supported, and included within their school community.

Bullying and FA

FA-related bullying has been identified as a common and pervasive problem in schools that impacts children and youth with FA, and their parents (Egan & Sicherer, 2016). Bullying is characterized by a misuse of power by a person or group of people towards another and is defined as repeated verbal, physical, and/or psychosocial behaviour that results in harm of the targeted (Fong et al., 2017). FA-related bullying may include verbal teasing or harassment about an allergy or wearing an EpiPen, receiving differential treatment, sitting at a segregated table, or overt physical acts of bullying such as being touched by an allergen, intentional contamination of food, or even being forced to ingest a possible allergen (Cooke et al., 2021; Lieberman et al., 2010). Bullying occurs most frequently within the school environment and those who are bullied

because of their FA are bullied repeatedly (Annunziato et al., 2014; Brown et al., 2021; Lieberman et al., 2010; Shemesh et al., 2013; Torabi et al., 2016).

Bullying because of FA represents a significant and well-documented concern within school settings. The prevalence of FA-related bullying among children and youth ranges from 20–34% (Brown et al., 2021; Cooke et al., 2021; Liberman et al., 2010; Rocheleau & Rocheleau, 2020; Shemesh et al.; Torabi et al., 2016) to as high as 42–60% (Fong et al., 2018; Muraro et al., 2014). Polloni et al. (2016) reported that 99% of teachers underestimate FA-related bullying, and only 4% indicated they had witnessed or been informed of such incidents. Remarkably, Liberman et al., found that 21% of reported bullying incidents were perpetrated by school staff. Bullying also extends to parents, most commonly from other parents, though incidents involving teachers and principals have also been documented (Brown et al., 2021; Cooke et al., 2021). Importantly, findings from Brown and colleagues indicate that schools with food bans have reported lower rates of bullying compared to those without bans.

Bullying can result in significant negative consequences on children and youth with FA, and their parents ranging from emotional, behavioural, and academic issues to overall lower QoL (Muraro et al., 2014; Shemesh et al., 2013). Children and youth who are bullied because of their FA can experience loss of self-esteem, shame, humiliation, sadness, depression, anxiety, and feelings of worthlessness (Cooke et al., 2021; Fong et al., 2018; Lieberman et al., 2010). Torabi et al. (2016) reported that some youth (ages 13-17) with a FA put themselves at risk by not wearing their medical identification bracelets for fear of being bullied. In addition, children or youth who experience bullying at school are at higher risk for school avoidance, poor academic outcomes, social rejection, and suicidal ideation (Annunziato et al., 2014; Cooke et al., 2021).

The literature indicates that FA-related bullying remains commonplace in school settings and is associated with increased distress and reduced QoL for children and youth with FA, as well as their parents (Nishida et al., 2025; Shemesh et al., 2012). Parents may be unaware that their child is being bullied, underscoring the need for greater awareness to support early intervention (Annunziato et al., 2014). Evidence-based reviews recommend zero-tolerance anti-bullying policies, FA education to increase awareness, and access to school-based mental health supports (Egan & Sicherer, 2016; Greenhawt et al., 2020). Collectively, these findings suggest that FA education and prevention efforts should target the entire school community, including staff, teachers, students, and parents.

Impact of Supportive Factors at School

Although much of the literature on FA within schools focuses on negative factors impacting children and youth with a FA, some of this literature has also identified factors within the school environment that help children, youth, and their parents feel safe and supported within the school community. School friends can serve as a buffer to the negative impacts of feeling different and social isolation at school (Anderson et al., 2021; Dupuis et al., 2020; Nishida et al., 2025). Children and youth with a FA that have supportive peers or peer champions can help shape positive school experiences, allow them to feel normal and can promote positive social experiences (Anderson et al., 2021; Dupuis et al., 2020; Elliot et al., 2015; Fenton et al., 2011, 2013; Sanagavarapu, 2020). For parents, open communication with teachers, standardized policies, increased education of FA, and psychological intervention are supportive factors that can build trust in keeping their child safe and ease their anxiety (Abrams et al., 2020a; Dupuis et al.; Sanagavarapu, 2018; Shahzad Mustafa et al., 2018). Supportive factors within the school environment have not been the focus of FA research; therefore, future research with this focus

may provide helpful recommendations which could inform changes that promote a safe, inclusive school environment for children and youth with a FA to thrive.

Canadian Law, FA Discourse, and Policy Implications

Public health policies and discourse in both academia and the media, have had considerable influence on how FA is managed, particularly in schools, over the last twenty years. The previous section on FA policy highlighted the most relevant and common policy issues pertaining to the school environment. This section will delve into a summary of how FA research and public discourse has evolved over time. Canadian law as it relates to FA will also be presented. Additionally, newly published clinical guidelines on the management of FA in schools has captured media attention and its potential implications will be addressed.

Evolution of Medical and Public Discourse of FA

Media portrayal of FA can influence public perception (Abo et al., 2017; Gupta et al., 2009). In particular, peanut allergies have become a contentious topic in both health literature and the media. While some in the medical community describe FA an emerging epidemic (Dean et al., 2016), others argue it is a case of population hysteria perpetuated by the medical community, legislation, allergy advocacy groups, and media narratives (Waggoner, 2013). Waggoner situates this debate historically, noting that in the 1970s was a pre-epidemic time when FA was considered a low-grade chronic condition with limited research attention. In context into the FA literature in tandem with public discourse dating back to the 1970s, which helps illuminate how the conversation around FA and focus of research has changed. Reports of peanut-related anaphylaxis fatalities in the 1980s and 1990s shifted discourse towards more alarming messaging such as “peanut allergy is the most worrisome food allergy issue confronting the pediatrician today because of all potentially allergenic foods, peanut appears to be the most

dangerous” (Schwartz, 1992, p. 654). Increased prevalence rates of FA began to be reported in the literature (Sicherer et al., 2001). It has been suggested that these increases may reflect inflated self-reporting influenced by increased public awareness (Harrington et al., 2011), though prevalence has continued to rise over the past three decades for reasons that remain unclear (Food Allergy Canada & CSACI, 2019).

In the early 2000s, FA organizations began to emerge, media coverage intensified, and warnings about everyday peanut exposures in schools became more prominent (Harrington et al., 2012). In 2002, Massachusetts became the first state to enact FA guidelines for schools, recommending peanut-free tables (Waggoner, 2013). Since then, similar policies including complete nut bans in schools began to take hold in the US and Canada changing the landscape within the school environments. Although intended to enhance safety, such policies have been criticized as extreme, not sufficiently evidence-based, and has generated public backlash (Harrington et al., 2012). Today, media debates continue to shape public understanding of FA.

Canadian Legislation and FA

In Canada, no national laws have been established to protect children with a FA. Rather, health and education laws are at the level of provincial jurisdiction, resulting in variable legislation across Canada (Food Allergy Canada, 2021). In 2005, *Sabrina’s Law* was the first piece of legislation in the world that put safeguards in place for students with FA (Ontario Laws, 2005). This landmark legislation requires families to disclose their child’s FA status to schools and require school boards to implement policies and procedures for FA prevention and management of anaphylaxis in schools. The law also exempts school staff from any liability, if in good faith, administer epinephrine when a student is experiencing anaphylaxis (Murdoch et al., 2018). Since then, most Canadian provinces have enacted legislation or established provincial

mandates although with noted variability (Feldman et al., 2022; Food Allergy Canada, 2021). For example, in 2019 Alberta passed *Bill 201*, which requires school boards to have a current emergency action plan (EAP) for every child with a FA and provide support for staff to administer epinephrine. Further, *Bill 201* requires all schools, public or private, to stock at minimum one EAI (Statutes of Alberta, 2019). While the *Public Schools Act* or *Bill 232* in Manitoba was amended to include a requirement for all school boards to have an anaphylaxis policy, it did not mandate stock EAI for schools (Food Allergy Canada, 2021; The Legislative Assembly of Manitoba, 2008). In contrast, Quebec does not have provincial legislation or mandates about FA policies leaving FA policies to be determined by local school policies.

While provincial legislation requires the development of FA policy in schools, Health Canada's food and drug regulations have addressed FA safety through product labelling. These regulations mandate that all prepackaged foods must declare priority food allergens on their food labels (Food Allergy Canada, n.d.). Laws governing FA labelling are helpful; however, responsibility for correctly interpreting labels and selecting safe foods ultimately rests with the person with a FA and/or their family. The constant daily vigilance required of families can lead to increased stress and unnecessary food restrictions may limit dietary variety or nutritional inadequacy (Mehta et al., 2013). Manufacturers have also begun to include precautionary allergen labels such as "may contain" or "made in a facility" to avoid risk of cross-contamination; however, this has resulted in confusion by consumers about its meaning. Consequently, the FA community has advocated for clarity and consistency on the precautionary allergen labels so families can make informed choices without unnecessarily limiting their food choices (Abrams et al., 2020a; 2020b).

In 2018, three Canadian lawyers, Murdoch, Caulfield, and Adams, sought to review law and human rights policy relevant to FA and how they might inform school policy. They determined according to both the Charter and human rights legislation; FA is a disability in Canada (Murdoch et al., 2018). Further, the Canadian Charter of Rights and Freedoms, which is part of the Canada's constitution, gives every person the right to freedom from discrimination based on their disability. Since FA is a disability, it is a legal requirement for Canadian schools to make sure children with FA do not face discrimination at school and are treated fairly (Murdoch et al., n.d.). Therefore, it is discriminatory to segregate a child with FA or exclude them from school related activities. After review of Canadian human rights cases about food bans, Murdoch et al. (2018), concluded that food bans for FA are not legally required due to evidence suggesting that they are not effective in reducing allergic reactions at schools.

Implications of Evidence-Informed Guidelines

In 2021, Wasserman and colleagues, a group of highly regarded FA experts, published evidence-informed guidelines for the prevention and management of allergic reactions in schools. The GRADE approach was used to classify recommendations as strong or conditional. Recommendations included FA training, stock epinephrine, EAPs, and avoiding the use of FA designated tables and school-wide food bans. All recommendations were graded as conditional due to reliance on expert consensus and low to very low quality of evidence.

One recommendation, discouraging site-wide food bans, garnered considerable media attention despite its limited evidence base. In 2021, headlines such as “Schools shouldn’t ban nuts, other allergens, new guidelines say” (Young, 2021) on Global News or the CBC news headline, “School bans don’t prevent allergic reactions...” (Hristova, 2021) dominated the news cycle. The implications of this messaging are significant given all the research demonstrating the

psychosocial burdens, FA-related bullying at schools, and decreased QoL families already experience. Further, to make recommendations to eliminate food bans in schools which was largely informed by two studies (Bartnikas et al., 2017; Cherkaoui et al., 2015), both assessed as low quality evidence may be premature given its contentious nature. Cherkaoui and colleagues found no difference in accidental exposure rates between schools that banned peanuts. They speculated that peanut-free policies provided a false sense of security among those that ban peanuts and/or those who did not ban peanuts were extra vigilant. Whether either are true require further research. Bartnikas and colleagues' retrospective review of epinephrine administration (2006–2011), reported no significant differences between self-designated “peanut-free” schools and those permitting peanuts. Notably, this was a result of two reactions that occurred in self-designated “peanut free” schools that did not serve peanuts at school but allowed nuts to be brought in from home. The considerable variability in how peanut free schools were able to self-designate is a limitation of the study which undermines its results. This underscores the need for schools to clearly define their nut restrictive policies. Further, having a clear policy in place is meaningless unless FA education and support for teachers and parents are provided to facilitate the understanding of such policies and how they are to be implemented.

Despite methodological limitations, these studies (Bartnikas et al., 2015; Cherkaoui et al., 2015) are frequently cited as evidence that food bans are ineffective. Such assertions overlook research showing that peanut-free guidelines do reduce peanuts in school (Banerjee et al., 2007), are associated with reduced allergic reactions (Abrams 2017b; Nguyen -Lu et al., 2012), and align with parental preferences (Elliot et al., 2015; Sanagavarapu et al., 2020). It undermines the progress made over years to change the discourse toward greater awareness and acceptance of FA, potentially placing children and youth at risk for stigma and exclusion (Dean et al., 2016).

Food bans may not prove to be the answer; however, it is clear that more research is required before schools can move away from abolishing food bans in schools. Furthermore, stakeholder input from the school environment including teachers, students, and parents are necessary to offer a balanced perspective on these issues.

FA and the COVID-19 Pandemic

The World Health Organization (WHO) declared COVID-19 a global pandemic in March 2020. In the years that followed this declaration, Canadians have had to live through various public health measures and restrictions to reduce the spread of the virus (WHO, 2019). The school environment including the teachers, staff, students, and parents have all been significantly affected by the pandemic. In 2020, Greenhawt et al.'s report highlighted recommendations for the management of FA during the pandemic. These recommendations included a shared responsibility of staff and students in adherence to vigilant handwashing, surface cleaning, and no food sharing. Elementary teachers interviewed during the COVID-19 pandemic, revealed that the perceived risk and responsibility for FA management in school was reduced due to remote learning and class cohorts (Santos et al., 2022; Santos, 2023). Further, although there was reduced nursing support and training, enhanced cleaning and seating arrangements because of pandemic restrictions positively influenced FA management within the school environment (Santos et al., 2022).

Children and youth with a FA were impacted by COVID-19 not only in school, but for other aspects of allergy management as well. Protudjer et al. (2021) examined the effects of the pandemic on quality of life in families with a child (0–8 years of age) with a FA. Families experienced unexpected challenges of food shopping such as availability of certain allergen-free foods, while mothers articulated that the day-to-day management of FA for their child was easier

as they were preparing all meals at home. That said, being isolated at home left some feeling overwhelmed without support. Families had to modify appointments for diagnosis with an allergist or delay oral immunotherapy because of the pandemic restrictions (Protudjer et al., 2021). Mack et al. (2020) reported that pandemic healthcare staff shortages and public health restrictions altered outpatient care such as allergy testing clinics and access to specialists such as allergists resulting in delays in OIT and oral food challenges. Moving forward post-pandemic, delivery of virtual care for lower-risk food allergy procedures such as online dose monitoring for OIT, early introduction of an allergen in low-risk infants, and follow-up care may have improved access to specialist care (Mack et al., 2020).

Non-published Research about FA Experiences within the School Environment

Five doctoral dissertations about children or youth with a FA or their parents were found during the literature search (Cathcart, 2022; Dobin-Williams, 2024; Johnson, 2024; Roberts, 2017; Zavell, 2019). Roberts used a case study design to explore the school experiences of children with life-threatening FAs and anaphylaxis as perceived by children, parents, teachers, and school administrators from a Canadian educational standpoint. Zavell used a phenomenological approach to explore the lived experiences of parenting children with FA. This US based research also had an education lens and revealed that parents of a child with a FA experienced anxiety, impacted their social world, and highlighted a need for universal policy and education in schools. Similarly, Dobin-Williams used an interpretive hermeneutic approach to capture the experiences of mothers of teenagers with a FA. Cathcart focused on the experiences of school-aged children with FA, parents, and their school caregivers at the beginning of the COVID-19 pandemic. More recently, Johnson used hermeneutic phenomenology with photovoice to explore the lived experiences of youth living with a FA. Results of this research

highlight that for youth; FA alters their sense of self, stressed the importance of their relationships with parents, and designated their home as a safe place.

Chapter Summary

The review of the FA literature underscores its significant impact on everyday experiences and the QoL in children, youth, and their parents. However, QoL research focusing on FA is marked by methodological variability, limited theoretical integration, and often lacks conceptual clarity. The Ecological Systems Theory (Bronfenbrenner, 1979; 1994) provides a useful framework for understanding children's experiences within the school context and has been applied in FA research (Anderson et al., 2021; Dupuis et al., 2020; Sanagavarapu, 2018). Further, Dunn Galvin and colleagues' conceptual frameworks strengthen our understanding of FA and will help inform future research and practice (2020). Despite limitations, the literature consistently demonstrates that the emotional, social, and economic impacts of FA which can contribute to a reduced QoL in the children and youth with a FA, and their parents (Lieberman et al., 2020). Recently developed FA specific QoL and anxiety tools show improved reliability and validity that hold promise as screening tools for use in clinical practice (Dahlsgaard et al., 2021; Poehacker et al., 2021). Review of FA policy clarified Canadian legislation and identified areas requiring further attention, including advocating for stock epinephrine and clarity around precautionary food labelling. The role of food bans in schools remains an ongoing issue and requires more rigorous evidence to guide future policy decisions. Overall, the literature supports the need for continued research into FA-related experiences of children, youth, and parents in the school environment in Canada and provides a foundation for this study.

Chapter 3

Theoretical Foundations

The purpose of this qualitative research is to gain a deeper understanding of the experiences of children and youth with FA, and their parents within the school environment. In this research study, I followed Crotty's (1998) scaffolded approach to outline the research process. According to Crotty, once the research purpose and aims are established four key elements must be addressed. Addressing these four elements of the research process will situate the research question in an epistemology, theoretical perspective, methodology, and methods which are all in alignment. This chapter addresses the first two elements of Crotty's scaffolded approach with Chapter 4 focusing on the methodology and methods. To best articulate this understanding within an interpretivist research paradigm, a relativist ontology with a social constructivist epistemology is embraced. More specifically, the philosophy of phenomenology will be the theoretical perspective used to guide this study as it aligns with the research purpose. Additionally, Bronfenbrenner's Ecological Systems Theory (1979, 1994) will be presented as a complimentary theory to phenomenology both of which align with the research objectives. The rationale for these theoretical foundations will be discussed with the intent that the research study will be strengthened by its transparency and commitment to ensure the methods and methodology used remain true to its ontological and epistemological underpinnings.

Ontological and Epistemological Assumptions

Given the primary research aim was to seek a deeper understanding of the experiences of children and youth with a FA and their parents, a first step is to articulate the ontological and epistemological assumptions which support the research purpose and guide this study (Wener & Woodgate, 2013). Within the interpretivist research paradigm, where the goal is to understand

meaning rather than seeking the truth (Bailey, 1997; Weaver & Olsen, 2006), a relativist ontology and social constructionist epistemology are embraced and highlighted below.

Ontology

Ontology can be defined as beliefs about the form and nature of reality (Killam, 2013; Laverty, 2003). Ontology “questions the real world and what can be known about it” (Welford et al., 2011, p.38). Two dichotomous ontological beliefs about reality are realism and relativism (Fletcher, 1996; Schantz, 2011). Realism, a historically dominant philosophy in human science research, is founded on the assertion that truth can be objectively studied and that universal truths are independent of human perception (Hirani et al., 2018). In this philosophical tradition, empirical knowledge is gained from scientific inquiry that can be quantified numerically (Bailey, 1997). While a realist ontology asserts that there is one objective truth, relativism, in contrast, maintains that there are multiple realities which are subjective in nature (Fletcher, 1996; Killam, 2013). A relativist ontology asserts that truth does not exist without meaning and truth is a relative concept that varies between individuals, groups, social forces and can change over time (Drummond, 2005; Hirani et al., 2018). Relativism embraces the notion that reality is created through human dialogue and interpreted within a certain context (Hirani et al., 2018). In consideration of these two opposing ontological assumptions, relativism is embraced in this research study as it is in keeping with the research purpose.

Epistemology

Ontology dictates one’s epistemological beliefs; that is, what the researcher believes about reality will shape the type of relationship the researcher has with what is being studied (Killam, 2013). Epistemology describes the relationship between the researcher and knowledge; therefore, the discovery of new knowledge is created through the interaction between the

researcher and that which is researched (Bailey, 1997). Through the lens of a relativist ontology, a social constructionist epistemology is appropriate for this study.

Social constructionism, as a subjective epistemological standpoint, holds several assumptions about truth and reality. Crotty (1998) views constructionism as “...the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interactions between human beings and their world and developed and transmitted with an essentially social context” (p.42). Embracing a social constructionist epistemology according to Crotty, is viewing the social and natural world not as distinct entities but co-existing as one human world. It is the task of the researcher to not uncover new truths about reality but to unmask an experience of reality that is constructed between human beings and their environment (Cruikshank, 2012). Construction of an experience is inextricably linked to history and culture. Constructivism is another epistemology that has been mistaken for constructionism. Crotty differentiates constructivism as individualistic understanding of social constructionism and focuses on the unique experience of each of us to make sense of the world. In contrast, social constructionism emphasizes the importance of historical and cultural influences on how we perceive the world and at different times and places, the same phenomena may be interpreted differently. This epistemological standpoint is important to embrace in this research study as it acknowledges participants' different backgrounds as unique and will shape how they experience FA in their everyday lives and at school. Further, changing cultural understandings and public perceptions of FA alongside an increased prevalence of FA in Canada continue to influence how FA is experienced.

Theoretical Perspectives

Phenomenology as a Philosophy

Phenomenology as a human science is based on complex philosophical traditions (Sundler et al., 2019). Phenomenology is divided into two main branches, descriptive and interpretive. According to Zahavi (2019), “anybody promoting a method, procedure, or approach that is supposed to merit the label ‘phenomenological’ should be familiar with phenomenological theory and with its philosophical origin” (p. 904). That said, turning to Husserl and Heidegger’s philosophical roots is a necessary step within the research process.

Husserl

Edmund Husserl (1859–1938), a German mathematician and philosopher, is best known as the founder of modern phenomenology (Lavery, 2003). Husserl’s work is recognized as descriptive phenomenology which embraces a realist ontology and a positivist epistemology (Cal & Tehmarn, 2016). According to Cal and Tehmarn, this infers that the observer is separate from the world, capable of being free of bias, and is able to understand a phenomenon or lived experience through its description before having the opportunity to reflect on that experience.

Husserl believed phenomenology is rooted in describing and understanding the essence of an experience as the fundamental nature of reality (Walters, 1995). The goal is to uncover the eidetic or essential features of a subjective experience, which are common to all individuals and therefore providing a basis for objective knowledge (Lopez & Willis, 2004). Husserl uses the term lifeworld to describe human experiences and defined the lifeworld as “...what we experience pre-reflectively, without resorting to categorization or conceptualization, and quite often includes what is taken for granted or those things that are common sense” (1970, cited in

Laverty, 2003, p.4). Thus, the key to understanding phenomenology is to seek to understand a pre-reflective experience before any interpretation can occur (Cal & Tehmarn, 2016).

Husserl's phenomenology is perhaps most well-known for the concept of phenomenological reduction (Zahavi, 2019). Phenomenological reduction is the change from a natural attitude to a philosophical attitude which involves questioning one's presuppositions about the world and reducing a complex phenomenon to its most basic components (Laverty, 2003). Phenomenological reduction involves the process of bracketing or epoché which means setting aside one's preconceptions and assumptions about the world so that one can solely focus on the experience itself (Crotty, 1998). Husserl explains that by bracketing external factors such as context, history, and culture one can gain a clearer understanding of the essence of an experience. In this regard, the researcher's approach is to take an objective stance in relation to the research participant's lived experience. Put simply, the researcher's personal lived experience, biases and assumptions are bracketed or set aside from the research process to minimize its influence on the data collected (Walters, 1995). According to Lopez and Willis (2004), researchers engaging in Husserl's phenomenology should not conduct a literature review prior to their research, nor should they prepare specific research questions. This stance positions itself with a positivistic view of the world where the researcher can remain objective (Cal & Tehmarn, 2016).

Husserl's phenomenology has played a significant role in the development of phenomenology today and has influenced a wide range of modern phenomenologists including Martin Heidegger, Merleau-Ponty, and van Manen (Laverty, 2003). Husserl's phenomenology differentiates itself from other phenomenologists in that it is viewed as a descriptive phenomenology rooted in a realist ontology and positivistic epistemology.

Heidegger

Martin Heidegger (1889–1976), another German philosopher, was influenced by Husserl's phenomenology (Cal & Tehmarn, 2016). While Husserl's phenomenology is known as descriptive, Heidegger's work is considered interpretive and is known as hermeneutic phenomenology (Lavery, 2003). The term hermeneutic is derived from the Greek God, Hermes, who was responsible for interpreting the messages between Gods (Lopez & Willis, 2004). Hermeneutic phenomenology goes beyond Husserl's description of lived experience and seeks not only to describe but also interpret the common core essence of everyday life experiences (Lopez & Willis, 2004; Cal & Tehmarn, 2016). Meanings are not always readily apparent to study participants; but rather, garnered from their narratives.

Heidegger rejected Husserl's concept of bracketing with the belief that it was not possible to bracket one's preconceived beliefs about an experience (Walters, 1995). He argued that our understanding of the world is always mediated by our pre-existing assumptions, beliefs, and cultural background (Lavery, 2003). Interpreting an experience is not simply a passive reflection of external reality, but rather, an active and creative process that shapes our understanding of reality (Cal & Tehmarn, 2016). Heidegger developed the concept of, Dasein, or being there, to describe human existence and hermeneutics is the process to which people interpret or make sense of the everyday world (Crotty, 1998). Research rooted in Heideggerian phenomenology rejects analyzing human experiences in the positivist sense; rather, embraces a subjective, social constructionist epistemology (Cal & Tehmarn, 2016). From this standpoint, Heideggerian phenomenology recognizes that value free observation is not possible and instead places value on the background and knowledge of the researcher. In contrast to Husserl, a literature search

and a researcher's prior knowledge and experience on the topic is useful and necessary in both identifying that research is needed and guiding it accordingly (Lopez & Willis, 2004).

After reviewing the philosophical origins of the two main branches of phenomenology, the philosophical roots of Husserl, are not in alignment with this study's purpose, ontology, or epistemology. Husserl's descriptive phenomenology is better positioned with a realist ontology and positivist epistemology. In particular, the concept of bracketing as described by Husserl, does not fit within a relativist ontology and aligns with a positivist epistemology. An interpretive phenomenological philosophy as espoused by Heidegger, is better suited to this study's research purpose and aligns with a relativist ontology and a social constructionist epistemology which is the foundation of this research study.

Ecological Systems Theory

The nature of this study requires consideration of the many relationships that are inherent to children and youths' experiences within the school environment. Bronfenbrenner's Ecological Systems Theory (1977, 1979, 1994), a theory about human development, was used in this study as a complement to hermeneutic phenomenology. The Ecological Systems Theory aligns with hermeneutic phenomenology in that it provides a complementary structure showing how a child's relationship and their many roles with their environment impacts development. It demonstrates how an individual is part of the larger environment and how these shape a child's experiences and development. Further, it illustrates the relationships that the parents have within the child's ecological system and therefore shapes parent experiences as well.

Bronfenbrenner' theory has been used in research focusing on various topics in a wide range of settings since its development (1977). His work has been referred to in various terms such as Ecological Theory (2011), Ecological Theoretical Framework (Sanagavarapu, 2017);

Ecological System's Framework (2018), Ecological Model of Health (Dupuis et al., 2020), Socio-Ecological Model (Runions et al., 2020), and the Bio-Ecological Systems Theory (El Zaatari & Maalouf, 2022). Despite different terminology and updates, the essence of his work remains and is thought to be one of the most accepted ways to demonstrate how environmental influences can shape human development (Guy-Evans, 2020). For this research, the name Ecological Systems Theory (EST) is used to remain true to its origins and intended purpose.

The core elements of the EST situate the child or youth at the centre of interrelated systems which influence the child's development (See Appendix C). The five ecological systems of the EST include the microsystem, mesosystem, exosystem, macrosystem, and chronosystem (Guy-Evans, 2020; Bronfenbrenner, 1994). These systems range from small settings that directly affect the individual to broader environmental contexts that have a more indirect influence on development (Ettekal & Mahoney, 2017). Understanding a child's development should not be reduced to a single system, instead emerging from an aggregate of interconnected and dynamic systems (Shestunova, 2022). Each of these systems and how they may relate to the proposed study are discussed below.

Microsystem

The first ecological system, the microsystem, describes the complex relationships with the child or youth in their immediate environment and is considered the most influential system within the EST (Bronfenbrenner, 1977; Guy-Evans, 2020). This system is represented by the people and their relationships who have direct contact with the child's immediate environment (El Zaatari & Maalouf, 2022). The environment is a physical place such as the home or school in which the child participates in activities in particular roles (e.g., student, daughter) and interacts with others in their environment. Relationships within this level are bidirectional, meaning that

interactions within the microsystem both influence the child's development and the child can also influence the actions and beliefs of those within their microsystem (Bronfenbrenner, 1977; Guy-Evans, 2020). Within the microsystem, emphasis is placed on the child's individual experiences and perceptions of their roles and activities within their environment (e.g., school). For this study, the microsystem is comprised of the child or youth's direct relationships with teachers, peers, and parents within the school environment. As experiences and relationships of children and youth extend beyond the school microsystem, the relationships within the microsystems of home (e.g., parents, siblings, grandparents) and community (e.g., coaches, neighbours) will also be explored. Bronfenbrenner (1994) noted that research typically focuses on how the microsystem at home impacts the child's school development. Exploring the school microsystem of children and youth with a FA may provide insight into how interactions within this setting influence functioning across other systems, including the home and broader community.

Mesosystem

The second system closest to the child or youth in Bronfenbrenner's (1977) EST is the mesosystem. The mesosystem includes the interaction of two or more microsystems or environments in which each developing child is actively participating (Bronfenbrenner, 1979). In the mesosystem, microsystems are interconnected and influence each other (Guy-Evans, 2020). Within the context of the research study, the mesosystem would include the interactions between the youth's microsystems of school and home and may include relationships with the youth's teachers and parents and/or classmates and siblings of the child.

Exosystem

The exosystem is the third system within the EST and is described by Bronfenbrenner (1977; 1979) as an extension of the mesosystem incorporating other formal and informal social structures. These social structures such or influencing systems affect the developing person but do not directly include the developing person and/or their microsystems (Guy-Evans, 2020; Michell et al., 2018). Examples of ecosystems indirect impact on a youth with a FA in the context of this study could be school boards (e.g., FA policy), local industry (e.g., Canadian food labels), local government (e.g., FA management and emergency preparedness training), or mass media (e.g., media coverage over FA such as food bans).

Macrosystem

The macrosystem within the EST (Ettetal & Mahoney, 2017) is the outermost system which describes the overarching beliefs, values, and norms within a society and culture in which the child is developing (Guy-Evans, 2020). According to Bronfenbrenner (1977), these beliefs and norms are reflected in culture, race, socioeconomic status and religious organizations. It has an indirect influence on all the other systems and can act as a lens through which individuals interpret their experiences (Ettetal & Mahoney, 2017). In Canada, there is much diversity in culture, race, and religion; therefore, articulating and understanding these influences on the developing child or youth in the school environment is paramount.

Chronosystem

The chronosystem is the fifth ecological added to the EST by Bronfenbrenner in 1994. According to Bronfenbrenner, “a chronosystem encompasses change or consistency over time not only in the characteristics of the person but also the environment in which that person lives” (p. 40). The chronosystem reflects historical events and life transitions that can impact

development. As a graphic, the chronosystem is depicted as an arrow (See Appendix C). In this study, the chronosystem represents the time in consideration of life transitions (e.g., beginning high school), and historical contexts (e.g., post Sabrina's Law, COVID-19 pandemic).

EST and Relevant Research

Since its development, the EST has been used both as a theoretical foundation for diverse research aims and as a framework for interpreting findings across multiple areas of child development. Although the EST has seen limited application in research involving children and youth with FA, a few studies do capture the complexity of relational dynamics within the school environment for students with a FA. First, a narrative review used the EST to examine research on the experiences of school children with chronic health conditions (Runions et al., 2020). Although not FA specific, FA is considered a chronic condition, therefore it demonstrates its relevance within the school environment. The study also underscores the interactions between microsystems of school and home. Dupuis et al. (2020) used the EST in their research to understand the experiences students and families managing FA in a US schools. The EST was used to report the findings from students and families. Sanagavarapu (2018) applied the EST to articulate that a child's successful transition to school is shaped by the microsystems of home, school, and community in her study exploring the experiences and support needs of mothers of a child with FA as they transition to school. More recently, Anderson et al. (2023) used the EST in their study exploring young adults' perspectives on their childhood experiences with FA. The results of this study aligned with the EST conceptualization of child development in that the closer the system is to the child (e.g., peer in school) the stronger the impact on the child. This study seeks to build on the previous research on FA using the EST as a foundation to the study and as a way in which the results may be reported and understood.

Chapter Summary

This chapter outlined the theoretical foundations of this study. Grounded in an interpretivist paradigm, the study embraces a relativist ontology and social constructivist epistemology. Hermeneutic phenomenology was identified as the guiding philosophical perspective, complemented by Bronfenbrenner's EST (1977, 1994) to situate lived experience within broader contextual systems. Together, the philosophical and theoretical perspectives ensure coherence and alignment with the chosen methodological approach. Chapter 4 will build on this foundation by detailing the methodology and methods employed in the study.

Chapter 4

Research Methodology and Methods

In keeping with Crotty's (1998) scaffolding approach to research, after the research purpose and questions are situated in an ontological, epistemological, and theoretical foundation, choosing a methodology and methods that are in alignment follow. In consideration of the study purpose, to gain an in-depth understanding of the lived experience of children and youth with a FA, and their parents, van Manen's (1997) hermeneutic phenomenology was an appropriate choice of research methodology and will be described. This chapter also outlines the data collection methods used to gain a deep and rich understanding of the participants' experiences.

Methodology

Hermeneutic phenomenology can be regarded as both philosophy and research methodology. In the previous chapter, the philosophical roots of phenomenology were introduced. Here, phenomenology as a methodology is presented in relation to this study. Unlike other social science research, phenomenology has no formal procedures or rules that need to be used universally (Briod, 2011). An approach to hermeneutic phenomenology used by van Manen (1997), combines elements of both Husserl and Heidegger to provide a practical research approach for nurses, doctors, and educators wishing to engage in phenomenological research in the human sciences. This approach is used as an overall guide to the methodology and informed the selection of methods in this study.

Hermeneutic Phenomenology as a Human Science

Hermeneutic phenomenology is an approach used in health sciences to gain a deeper understanding of the nature or meaning of everyday experiences or lived experience (van Manen, 1997, 2017). According to van Manen (1997), "phenomenology describes how one orients to

lived experience [and] hermeneutics describes how one interprets the ‘texts’ of life” (p.4). This type of research seeks to construct an interpretive description of some part of the lifeworld and their meanings as they occur in our everyday lives with depth and richness. According to a contemporary Canadian phenomenologist Max van Manen (1997), the fundamental question of hermeneutic phenomenology is “What is an experience like?”, and used as a method in hermeneutic phenomenology, emphasizes a textual reflection of the lived experience to expose what is at the essence of a particular phenomenon.

The phenomenological approach to research methodology developed by van Manen (1997) is rooted in the work of the two aforementioned philosophers Edmund Husserl and Martin Heidegger. While Husserl and Heidegger take a philosophical approach to understanding the lived experience, van Manen’s approach is centered on the notion that the lived experience of everyday life is the source of knowledge. That said, the study of lived experience as described by van Manen (1997, 2014, 2017) draws on several key concepts that blend both Husserl and Heidegger’s philosophical roots. Like Husserl and Heidegger, van Manen’s research methodology focuses on the subjective first-person experiences of individuals. Van Manen emphasizes the importance of language in the construction, communication, and understanding of the world. Like, Husserl, van Manen embrace phenomenological reflection; however, he departs from his approach to epoché and reduction. While van Manen does not completely reject epoché and reduction, he questions if this can be fully achieved in practice and aligns with Heidegger arguing that it may not be possible, practical, or justified to bracket information as beliefs and assumptions because they are so deeply entrenched in everyday experiences (van Manen, 2014; Zahavi, 2019). Instead, van Manen recommends researchers make their prior knowledge and assumptions explicit rather than attempting to engage in reduction (1997). This

approach is in keeping with this qualitative research which grounded in relativist ontology and social constructionist epistemology. Further, as a novice researcher and parent of a child with FA, this pre-existing knowledge and life experience is embraced as an asset to the research process. Although every effort was taken to turn to the lived experience of participants and remain open to their descriptions, having personal prior knowledge was beneficial in establishing credibility and rapport. In addition, having personal experience may have facilitated a deeper exploration into participant experiences that might otherwise remain unexplored.

Given these assertions, hermeneutic phenomenology is not an empirical science, nor does its description offer a full universal truth of an experience. It does not rely on objective data; but instead, remains subjective, relying on phenomenological examples from a study's participants (van Manen, 2017). For this study, these phenomenological examples were drawn from verbatim transcripts of participant interviews and ecomaps through their recollection of experiences through detailed experiential accounts, stories, anecdotes, and as well, my field notes.

Methodical Themes

This study was informed by hermeneutic phenomenology as described by Max van Manen (1997, 2014). He outlines six methodological themes to guide inquiry into lived experience: turning to the nature of lived experience, investigating experience as we live it, hermeneutic phenomenological reflection, hermeneutic phenomenological writing, maintaining a strong and oriented relation, and balancing the research context by considering the parts and whole. These themes will be highlighted below. Within the hermeneutic phenomenological reflection methodological theme, five existentials are described and were used as a framework for presentation of findings in this study.

Turning to the Nature of Lived Experience

Turning to the nature of lived experience is the first methodical theme outlined by van Manen (1997) when engaging in hermeneutic phenomenology and can be understood as the preparatory phase of the research process. This involves making an unwavering commitment by the researcher to make sense of the phenomenon of interest (Earle, 2010). According to Blair-Lawton (2016), this is first reflected in the foundational thinking that shapes the research question, literature review, articulation of pre-understandings, development of the research proposal, and recruitment of participants. With this approach, the concept of bracketing is rejected and instead the researcher's knowledge about the phenomenon or experience is made explicit (Earle, 2010). Van Manen (1997) believes the researcher is an active participant in the research process and views knowledge or pre-understanding of the phenomenon of interest as essential and can facilitate the description, interpretation, and understanding of the lived experience of participants.

Investigating Experience as We Live It

This methodological approach requires the researcher to become immersed in the phenomena or experience of interest for a deep understanding to develop. Here, van Manen (1997) asserts that the researcher's personal experience is the starting point for research. These personal experiences can be an asset to the research process in that they may provide context and insights that may facilitate the interview and the data analysis phase. From here, research data is collected through writing, observation, and interviewing (Earle, 2010). Exploring the lived experience of a certain phenomena can be achieved through multiple in-depth interviews of the research participants (Blair-Lawton, 2016; van Manen, 1997). Interviews collect rich data about an experience; as well, create a dialogue between the researcher and participant that allows

discussion about the meaning of that experience (Earle, 2010). A second interview is valuable in hermeneutic phenomenology as it fosters relational trust and openness, provides an opportunity to expand on initial narratives, and allows an opportunity to clarify emerging insights thereby deepening the understanding of experiences (van Manen, 1997, 2014).

Hermeneutic Phenomenological Reflection

Fundamental to hermeneutic phenomenological human science research is to explore the lifeworld experienced through everyday situations and relationships (van Manen, 1997). The concept of the lifeworld is key to understanding human experience and refers to the world as experienced and interpreted by people in their everyday lives. Van Manen asserts that the lifeworld encompasses the complexity of human experience including the physical, social, cultural and historical aspects of everyday life. The lifeworld is not merely a passive backdrop to human experiences, rather it actively influences perceptions, emotions, and actions.

Hermeneutic phenomenological reflection, according to van Manen (1997, 2014, 2017) takes into account five existentials to reflect, analyze and understand the meaning of lived experience: lived space (spatiality), lived body (corporeality), lived time (temporality), lived relations (relationality), and lived things (materiality). These existentials are interwoven with each other and fundamental to understanding the complexity of human experience (Basnet, 2022). *Lived space* refers to the physical world in which people exist and the way their environment shapes their perception of experiences. Lived space can include both the natural world and the built world including our homes and work environments (van Manen, 1997). The experience of lived space is not limited to visual perceptions but also include sensory and emotional responses to their environments. Next, *lived body*, refers to the way in which our bodies shape our experiences of the world. Lived body includes our body movements, and our

senses, and emotions and how they are perceived within the context of an experience. *Lived time*, as described by van Manen refers to how one makes sense of the world and incorporates our cultural, historical, personal contexts, and as well, one's beliefs and values. Here, van Manen aligns with Heidegger in his belief that lived experience in the present cannot be separated from the historical and cultural contexts. The fourth existential van Manen describes is lived human relation. *Lived relation* is how individuals interact and understand others in their everyday lives. Individuals interact with others within the context of their own unique experiences and perceptions of the lifeworld and need to consider the others interpretation. Understanding others' experiences involves a process of interpretation and understanding. In doing so, it can promote empathy, deeper understanding, and meaningful connection between people (van Manen, 1997, 2014). Finally, *lived things*, was added as the fifth existential that belong to the lifeworld. Lived things is an existential that conveys how people experience and engage with the physical objects, technologies, and the material world (2014). Together, these five existentials served as a guide to hermeneutic phenomenological reflection, informing supporting the interpretation of meaning of a lived experience.

Phenomenological reflection is a research activity described by van Manen (1997) as the primary means of discovering the essence of the phenomena or experiences. Essential themes derived from two interviews per participant and their verbatim transcripts, ecomaps, writing, and observations give structure to the elucidate the lived experience (Earle, 2010). Hermeneutic phenomenological reflection continued throughout the data collection and analysis phases. Field notes were also documented to support the process of reflection and were used throughout data collection and analysis.

Hermeneutic Phenomenological Writing

Researchers seek to elucidate meaning of the experience by analyzing texts from interview transcripts (Paley, 2018). This process entails writing and rewriting themes derived from participant interviews and/or observations (Lawton, 2016, van Manen, 1997). A key aspect of hermeneutic phenomenology research is writing and rewriting research texts to elucidate meaning about the phenomena or experience in question so that the final research text is a recognizable lived experience for the reader. The act of reading and writing text from the interview data should always maintain a questioning attitude particularly when the focus is on the lives of children (van Manen, M.A., 2017).

Maintaining a Strong and Oriented Relation

Engaging in human science research using a hermeneutic phenomenological approach requires that the research maintains a strong and oriented relation to the research purpose (van Manen, 1997). According to van Manen, this requires a strong focus throughout the research process without getting side-tracked with speculative opinion or superficial analysis of an experience. Blair-Lawton (2016) describes this methodological theme as always keeping the research purpose and aims in relation to the literature and the interview data throughout the research process.

Balancing the Research Context by Considering the Parts and the Whole

Similar to Heidegger's hermeneutic circle which describes a process of understanding an experience by moving back and forth from focusing on parts of an experience to the whole experience (Crotty, 1998), van Manen describes this concept of considering the parts and the whole of an experience as an ongoing process (1997). Ajjawi and Higgs (2007) described the hermeneutic circle as a metaphor for understanding and interpretation of which is the movement

between parts (i.e., interview transcripts, ecomaps, fieldnotes) and the whole (i.e., an evolving understanding of the experience). This process is not considered a final step, rather, an ongoing process throughout the data collection and analysis phases (Blair-Lawton, 2016). It is through this process that themes began to emerge and illuminate the lived experience (van Manen, 2017).

Methods

Methods are specific techniques and procedures used to collect and analyze data that relate to the research purpose (Rehman & Alharthi, 2016). The ontology, epistemology, theoretical perspectives, and methodology chosen to best reflect the study purpose also serves to inform the choice of methods for the study and are described below (Crotty, 1997).

Sample

Purposive and Snowball Sampling and the Target Population

Purposive sampling and snowball sampling were both used to recruit the target population. Initially, the target population for this study was youth living in Canada (ages 12-17) with a self-reported diagnosis of a FA who were prescribed an EAI, and their parents. All participants had to be able to speak English. Youth and their parents needed to be or have been enrolled in a public or private school in Canada. Participants who wanted to take part in the interviews through a video conference, needed to have access to technology such as a phone or computer. After limited inquiries from youth and their parents and greater interest from parents of younger children, the inclusion criteria were expanded on March 11, 2024, to include a broader age range; children (ages 8 – 11) and youth (ages 12 – 19). The lower age was set at eight years as this developmental stage reflects the transition at which children begin to recognize the limits of parental control over allergic reactions and demonstrate more complex cognitive, emotional, and behavioural coping strategies (Dunn Galvin et al., 2009).

Sample Recruitment

Participants for this research study were recruited using various approaches. A recruitment poster was developed to use on social media and as a hard copy (See Appendix D). First, parents and youth across Canada were recruited using social media platforms such as X (formerly known as Twitter), Facebook, and Instagram. Additionally, recruitment was conducted through word of mouth and hard-copy posters. These posters were distributed in community settings in Winnipeg, MB and surrounding areas and the central Okanagan, BC as appropriate. These settings were chosen because of my existing personal or professional networks, reflecting pragmatic considerations rather than any defining characteristics about the communities themselves, and were meant to complement a national recruitment approach. Potential participants who showed interest in the study were sent an introductory email about the study, eligibility requirements, time commitment, interview format options (in-person or video call). Participant recruitment began mid-February 2024 and continued to October 2024. The initial recruitment poster was posted on Facebook, Instagram, and X. Hardcopies were also distributed where permitted. An updated recruitment poster (see Appendix E) was used after an amendment approval was granted March 11, 2024, which opened up the study to include children or youth (ages 8 – 19) with a FA. All children or youth who participated in this study did so because of parental involvement in the study. It is unclear how many participants were recruited through snowball sampling, however at least one participant articulated that they learned about the study from another mother of a child with FA in her community.

Sample Size

Although the means to ascertaining sample size in qualitative studies is not determined in the same way as a quantitative study, the size of the sample is still given consideration (Malterud

et al., 2016). Saturation, a concept developed first by Glaser and Strauss (1999), has typically been used to determine sample size in qualitative studies in the past; however, reviews of qualitative research suggest a lack of transparency about determining sample size and how saturation was achieved (Carlson & Glenton, 2011). In response to a perceived lack of guidance for qualitative researchers in planning for sample size, Malterud and colleagues developed the concept of information power and recommend using information power as an alternative to saturation to guide the sample size determination in qualitative research. They assert that the more relevant information that a sample holds in relation to the study, the lower the sample size that is required. These authors recommend that a sample size with adequate information power depends on the following: the aim of the study, sample specificity, use of established theory, quality of dialogue from the interviews, and the analysis strategy.

All components of information power, apart from quality of dialogue, were considered in the planning of the study. In this study, the aim of the research was to gain an increased understanding of the lived experience of children and youth with a FA, and their parents within the school environment. The participants, children and youth with FA, and their parents, are highly specific to the research focus. The research study used established theory, informed by hermeneutic phenomenology (van Manen, 2014) and the EST (Bronfenbrenner, 1977, 1994). Research methods that engage in an in-depth analysis of interviews, such as van Manen's hermeneutic phenomenology, require less participants. With these aforementioned criteria for information power considered, it was estimated that 10 families were needed for participation in this study. This estimation could have been amended based on recruitment accrual and initial analysis of data but was not required due to assessment of the quality of data by myself, and in consultation with my advisor.

Setting

Interviews occurred in-person or by video conference depending on location of participants and participant preference. In-person interviews were offered to participants recruited in Kelowna, BC and surrounding Okanagan communities and Winnipeg, MB and surrounding communities because they were accessible to the researcher. Interviews were conducted in a setting at a time and location of participant choosing (i.e., home, public meeting space, school class or meeting room). Participants were also given the option of a video interview via Zoom if it was more convenient or comfortable for them or if they resided outside of the Okanagan or Winnipeg areas.

Data Collection

All data collected for this study was purposefully directed toward describing and understanding the meaning of the lived experiences of FA. Prior to data collection, ethical approval from the Research and Ethics Board (REB) at the University of Manitoba was obtained February 14, 2024. An information sheet about the study along with an informed consent form was given to those interested in participating in the study. Data was collected using a demographic form, semi-structured interviews, and ecomaps created by participants. Field notes including a personal reflection were also completed after each interview.

Demographic Forms

Children, youth, and parents who participated in this study were given a demographic form to complete prior to the semi-structured interviews. The demographic forms, for parents or caregivers (See Appendix F) and children or youth with a FA (see Appendix G) were developed in consultation with my advisor. These forms were developed to ascertain demographic data about the participants, as well as key information about their FA and school policy. The forms

were created so that completion time was estimated to be no longer than 5 minutes. Demographic forms were sent by email or mail and received by email, mail, or in-person.

Semi-Structured Interviews

Repeated, open-ended interviews are an important feature to hermeneutic phenomenology as it allows for detailed descriptions of the pre-reflexive experiences to emerge (van Manen, 1997; Woodgate et al., 2020). Engaging in more than one interview is not only a feature of phenomenology but is also recommended when children are participants, as it gives the opportunity to build trust between the researcher and the child (Woodgate, 2000). An additional interview allows for follow up on themes identified in the initial interview. Children and youth with a FA, and their parent(s), participated in two semi-structured interviews conducted either in person or via videoconference. Families could choose to be interviewed together or separately to promote agency and comfort. This flexibility acknowledges that parental presence may support participation but also could influence or limit a child or youth's response (Gardner & Randall, 2012). For the initial interviews, interview guides were developed for parents/caregivers (Appendix H) and for children and youth (Appendix I). Participants were invited to share their experiences of FA broadly and within the school environment. Participant-created ecomaps were introduced at different points to guide discussion, alongside strategies such as silence, active listening, prompting, and clarification (Jasper, 1994; Woodgate et al., 2020). The second interview provided an opportunity for both the participants and me to reflect on the initial interview, clarify or expand on responses, and contribute to emerging themes. All interviews were digitally recorded and later transcribed verbatim to preserve their authenticity. Parent interviews ranged from 16 to 76 minutes, and child/youth interviews from 12 to 46 minutes, with first interviews longer than the second.

Ecomaps

Ecomaps are a graphic portrayal of an individual's relationships and social and supportive networks across people and environments (Ray, 2005) and can generate rich qualitative data while enhancing rigour and supporting both data generation and analysis (Manja et al., 2021; Rempel et al., 2007). According to Baumgartner and Buchanan, (2010), ecomaps are useful for identifying micro and meso-systems within Bronfenbrenner's EST. The methodological framework, *Journey Mapping in Applied Public Health and Social Sciences (J-MAPHS)* developed by Woodgate et al. (2026), informed the use of ecomaps in this study. This framework draws on four complementary frameworks that emphasize an inclusive, people-centred, trauma-informed, and action-oriented approach. Woodgate et al.'s framework provides best practice guidance for the use of ecomaps through a stepwise approach, including participant instructions, journey map creation, interview processes, and analysis. For this study, an instruction sheet, adapted with permission from Woodgate (2022) on how to create an ecomap was given to the research participants (See Appendix J). Examples were provided which conveyed different types of lines and/or colours to depict relationships, social connections, activities, or environments (Woodgate et al., 2021). With respect to this study, ecomaps served two purposes: to guide discussion during interviews and to provide rich data that supplemented participant interviews.

Field Notes

Field notes are an essential component to qualitative research as they can enhance data and provide a rich context for data analysis (Phillippi & Lauderdale, 2018). Field notes function to help construct rich descriptions that situate the study in time, place, and/or population.

In hermeneutic phenomenology, field notes are an important tool used in the data collection phase and should be detailed and comprehensive. It requires the researcher to immerse oneself in the experience being studied to assist in capturing the essence of experience through descriptive and interpretive notes (Arrey et al., 2019). A field note guide, developed by Woodgate (2019) was used with permission to provide a working framework (See Appendix K). The structure of the field notes included four sections: descriptive notes, theoretical notes, methodological notes, and reflective notes. The field notes included raw data from interviews, personal reflections, and detailed descriptions to enhance the recollection of events in the setting. They were written immediately after each interview session. In this study, field notes were also helpful to reflect on each interview for areas of content that needed to be explored more fully and informed the second interview with participants. See Table 2 for some excerpts from field notes.

Table 2

Field Note Excerpts

Field Note Type	Example	Comments
Descriptive Notes	“Interview conducted at ~11am–1pm in participant home.” “I was invited to conduct the interview at the kitchen table. All family members were present at the time of interview including female youth with food allergy, younger sibling, mother and father. When given the choice, it was decided that the youth participant would participate in the interview first. Her mother was present for all of the interview and took her own notes occasionally to remind her of some key points she wanted to speak to in her interview. The younger sibling was not present for the majority of the interviews but did pop in occasionally. This caused no interruptions to the flow of the interviews.”	These notes document observations about the conditions of the interview. During analysis, they were helpful in data analysis as they provided context as to why certain topics were discussed. In this example, the presence of the youth’s mother may have impacted what was shared.

Theoretical Notes	“Parent volunteers were not given any education about food allergy or how to identify signs of anaphylaxis or choking. From this mom’s experience in 3 different schools (2 eating in classroom, 1 cafeteria) supervision at lunch hour was not done by teachers, rather parent volunteers. To her knowledge, there was no communication or education given to these volunteers about food allergy.”	This example was highlighted in this section as I recognized this as an important element of the interview as a potential key finding.
Methodological Notes	“Ecomaps are a good way to start these interviews. Focusing on and allowing participants to begin by describing the ecomaps was a good ‘icebreaker’.” “Some of the questions became redundant during the interview as they were already covered when participants were describing their ecomaps.”	Notes such as these allowed me to adjust questions for next interviews. It also reinforced what was working well (e.g., using ecomaps to start first interview), but being aware that there was some overlap. This allowed me to let other participants expand as much as they felt comfortable when reviewing ecomaps.
Reflective Notes	“I have also noticed that no bullying or teasing is occurring with this family or others. I wonder if this is in part due to the FA policy, overall, FA tolerance in our society, an anti-bullying message in schools generally, and an acceptance in society about various diets, intolerances, and allergies more common place? (link to EST - Macrosystem)”	This example provides insight into my reflections on participant experiences. I ponder what I am observing and what this might mean. Here, I also begin to make connections between experiences in relation to the EST.

Data Storage

Parents, children, and youth were informed that all data collected would be de-identified to maintain confidentiality. All electronic data, participant codes, and transcripts have been stored in a locked, secure data base in alignment with the standards set out by the University of Manitoba Research Ethics Board. Dr. Woodgate and I are the only two individuals who have access to the passwords and participant codes.

Honorarium

Parents who participated in this study were sent an electronic gift card of their preference in the amount of \$25 as a gesture of appreciation for their time. Child and youth participants

were also given an age-appropriate gift card of the same value. Examples of gift cards sent out to participants were Walmart, Indigo, and Amazon.

Data Analysis

The goal of data analysis in a hermeneutic phenomenological study is to “transform lived experience into a textual expression of its essence—in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful” (van Manen, 1997, p.36). Researchers involved in data analysis using hermeneutic phenomenology aim to represent the findings in a way that remains faithful to the data yet remain accessible to others. Researchers strive to create an evocative description that is both straightforward and rich in depth, so that readers of this text will engage in a phenomenological nod in recognition of this experience that is in keeping with their own. In accordance with a hermeneutic phenomenological approach, meaning of an experience can emerge by analyzing the description of the interviews (Woodgate, 2000). A critical step in data analysis grounded in phenomenology is moving back and forth from an understanding of the whole text to specific themes as described by Heidegger’s hermeneutic circle (Ajjawi & Higgs, 2007; Crotty, 1998). Data analysis of the transcripts began with a naive reading of each interview by the researcher and advisor to get sense of the overall meanings of the interviews. Next, a detailed line-by-line approach was used (Arrey et al., 2019). Each sentence was reviewed with a constant questioning about what was being revealed about the experiences that were described (van Manen, 1997). Key words and phrases were underlined, with initial themes developed in the margins of the text. After the researcher and advisor agreed, the subthemes were grouped into main themes according to each of van Manen’s five existentials. The overarching theme was then developed from an iterative examination of five themes and their subthemes. The use of the EST (Bronfenbrenner, 1979)

provided an additional lens for data analysis. Consideration was given to the data in relation to how the participants' ecological systems (i.e., microsystems, mesosystems, exosystem, macrosystem, chronosystem) interacted and shaped the lived experiences of FA.

Trustworthiness

In keeping with Heidegger's philosophical stance on hermeneutic phenomenology, researchers engaging in hermeneutic phenomenology as a method seek to both describe and interpret the experiences of the phenomena of interest (Cal & Tehmarn, 2016). It is not the intent that the experiences presented in this qualitative study will be representative of all those who experience living with a FA, and therefore, may not be transferable across all families' experiences in schools (Jasper, 1994). Every child, youth, and parent will have a different experience within their unique lifeworld. Validity in the context of phenomenological research is based on the uniqueness of the lived experience of each participant, whilst allowing for an understanding of the meaning of the experience itself (Jasper, 2018).

To maintain methodological rigour in phenomenology, trustworthiness must be established throughout the research process. Trustworthiness of the research was established by addressing the following: credibility, dependability, confirmability (Guba, 1981), and balancing participant meaning of experiences with researcher interpretation (Williams & Morrow, 2009). Credibility, or how congruent is the data with reality, has been addressed through data triangulation (e.g., use of two interviews per participant, field notes, ecomaps), investigator triangulation amongst the researcher and advisor, and theoretical triangulation (e.g., use of hermeneutic phenomenology, the EST, and supporting literature) to understand the research findings (Stahl & King, 2020). Dependability, or maintaining the integrity of the data over time, requires a clear articulation of the methods allowing for the replication of the study procedures

(Williams & Morrow, 2009). Clearly articulating the study methodology and methods was an important first step. Confirmability was achieved through reflexivity and debriefing between myself and Dr. Woodgate (Ahmed, 2024). Williams and Morrow posit that balancing participant meaning and researcher interpretation is an important aspect of trustworthiness. This has been particularly important in this study and required a balance of subjectivity (i.e., acknowledging bias) and reflexivity (i.e., awareness of self through reflection). As a novice researcher, it was paramount to obtain ongoing feedback from my advisor regarding quality and quantity of data. According to Tavakol and Sanders (2025), trustworthiness also requires a depth and fidelity to lived experiences. That is, rich descriptions by using direct quotes from participants help preserve the context and original meaning. In this study, direct quotes and ecomaps were used to give voice to participants and to help ensure researcher interpretations were appropriate. Field notes, particularly the reflective notes, were beneficial in assisting me to recognize my own experiences as separate from participant stories.

Ethical Considerations

As the researcher, I have adhered to the ethical principles of autonomy, non-maleficence, beneficence, justice, and confidentiality to safeguard the rights of the research participants. Formal approval from the Research Ethics Board (REB) from the University of Manitoba was obtained prior to data collection on February 14, 2024, with an amendment to inclusion criteria approval on March 11, 2024. This study protocol received annual renewal approval February 4, 2025, and January 17, 2026. Written consent was obtained from research participants over the age of 18 (Appendix L) and assent for child (Appendix M) and youth participants (Appendix N). Although every effort was made during the research process to minimize risks to youth and parents, contact information for support (Appendix O) was provided to the families participating

should the interview process result in any unpleasant feelings or distress. Strategies were employed to minimize the possibility of participant identification using pseudonyms and/or participant numbers. All participants were given pseudonyms that were used in the presentation of findings. Additionally, numbers were assigned to each participant and used to cite examples in the presentation of findings (e.g., P01, Interview 10). Further, any name of schools or community programs were de-identified to further protect participant identity. All audio recordings have been stored in a locked drawer and Dr. Woodgate and myself are the only two who have access to the original transcripts.

Chapter Summary

The first four chapters of this dissertation provide a clear and solid foundation, grounded in a thorough review of the literature, exploration of the theoretical foundations of hermeneutic phenomenology and Bronfenbrenner's EST (1977, 1994), along with van Manen's methodological approach (2014). Together, these chapters establish the conceptual and methodological grounding to address the research questions. To restate, the overall purpose of this study was to obtain a deeper understanding of the lived experience of children and youth with a FA, along with their parents within the school environment. Data collected for this study included demographic forms, two semi-structured interviews with each participant, ecomaps, and fieldnotes. Methodological rigour, consistent with van Manen's approach to qualitative research and the ethical standards as outlined by the University of Manitoba, were upheld throughout the study. The following two chapters present the findings of this study. Chapter 5 focuses on the demographic profile of the participants, while Chapter 6 presents the findings derived from participant interviews and ecomaps.

Chapter 5

Participants Profiles

This chapter presents the demographic profile of all study participants which included children and youth with a FA, and their parents. All data were obtained from demographic forms completed prior to the interviews. This chapter begins with an overview of participant characteristics, followed by a description of relevant health history of children and youth, EAI-related information, and reported school policy. Next, a brief discussion about the ecomaps collected and the length of participant interviews by children, youth, and parents is presented.

Demographic Profile of Participants

Ten families participated in the study, with 21 total participants. Parent participants included eight mothers and four fathers. Some parents chose to participate as a pair ($n=3$ mother/father dyads), while one parent participated in the interviews for other families (mothers, $n=5$ and fathers $n=1$). Two of the mothers indicated that they were separated, while the reasons for the other parents not participating were not provided. One mother participated without her child present citing that her child had a quiet temperament and ongoing anxiety.

Nine children and youth with a FA participated in this study. Child participants included two females (age 8) and two males (ages 10 and 11). The average age of child participants was 9.25 years (median=9). Five youth participated: three males (ages 12 and 16) and two females (ages 14 and 15). The average age of youth participants was 14.6 years (median=15). All parents, children, and youth participants identified as either male (he/him/his) or female (she/her/hers). One 15-year-old youth participated without a parent. See Table 3 for a summary of the age and gender child, youth, and parent participants.

Table 3*Age and Gender Profile of Participants*

Participants	Boy/Man	Girl/Woman
Mothers	-	n = 8
Fathers	n = 4	-
Children (8-11 years)	n = 2	n = 2
Youth (12-19 years)	n = 3	n = 2
Total (n = 21)	n = 9	n = 12

Geographical Location

All participants were Canadians and currently residing in Canada. Four families were from Manitoba (three from Winnipeg and one from a rural Manitoba location). Six families were from British Columbia including one from the Greater Vancouver Area and five from Kelowna, West Kelowna, or Lake Country in the Okanagan Region.

Participant Ethnicity

Participants were asked to identify their ethnic backgrounds on the demographic form. Over half identified as Caucasian (57%, n=12). Two participants identified as Southeast Asian (9.5%) and two as East Asian (9.5%). One participant identified as Metis (4.8%), one as other or multi-ethnic (4.8%), and three participants did not answer this question (14.3%).

Parent Education, Income, and Marital Status

The majority (83%) of parent participants were married (n=10), while two parents noted that they were separated or divorced (17%). All children of married parents lived full-time with their parents and siblings. It is unclear how custody was shared with children of parents who

were no longer together. All parents were educated beyond a high school diploma, ranging from a college diploma (n=4 or 33%), bachelor's degree (n=6 or 50%), to a master's degree (n=2 or 17%). Reported household income was variable. There was one participant in each of the following annual household income range: \$25,000–50, 000, \$75,001–100,000, and \$100,001–125,000). Half of parent participants (n=6) reported an annual family income exceeding \$150,000. Three parents (25%) did not to disclose their income.

Siblings

All children or youth, but one, reported having one or more siblings. One child had two older siblings, and three children reported having one younger sibling in the home. Two youth reported having younger siblings, one reported having an older sibling, and one reported having both a younger and older sibling. One child reported being the only child in the household. Notably, one youth reported having an older sibling with the same allergy.

Allergen and Medical History of Children and Youth

All children and youth reported at least one FA. Allergies to peanuts and/or tree nuts were the most prevalent (8 out of 9 child and youth participants; 89%). Other noted food allergens included seafood (n=3), sesame (n=2), dairy (n=1), eggs (n=2), green peas, and soy (n=1). Five participants (n=3 children, n=2 youth) had experienced anaphylaxis requiring the use of an EAI. No child or youth reported receiving an EpiPen at school; however, one youth participant had required an EpiPen while attending a school day camp (see Table 4).

The medical history of the children and youth participants was provided by their parents. Three participants had no other medical history documented other than their FA. Medical conditions reported included asthma (n=4), eczema (n=3), autism spectrum disorder (n=1), attention deficit hyperactivity disorder or ADHD (n=1), anxiety (n=1), and hyperglycemia (n =

1). The number of children or youth in this sample who experience anxiety may be higher than reported on the demographic form as many parents, children, and/or youth disclosed having had feelings of anxiety or worry during the interviews. Table 4 provides a summary of participants FAs and other medical history.

Table 4

Medical History of Children and Youth

Child or Youth by Age	Allergen (s)	Medical History	Previous Use of EAI	Use of EAI at School
8 (F)	Tree Nuts: Cashew & Pistachio	None	No	No
8 (F)	Peanuts Tree Nuts: Cashew & Pistachio Sesame Dairy Pink Fish	Asthma	Yes	No
10 (M)	Peanuts Tree Nuts	Eczema	Yes	No
11 (M)	Peanuts Tree Nuts Seafood Eggs	Anxiety Asthma Eczema	Yes	No
12 (M)	Eggs	ADHD	Yes	At Day Camp
14 (F)	Tree Nuts: Cashew & Pistachio	None	No	No
15 (F)	Peanuts Tree Nuts	Asthma Autism	No	No
16 (M)	Peanuts Tree Nuts Seafood	Asthma Eczema	Yes, at hospital	No
16 (M)	Peanuts	None	No	No
*10 (M) Not in study, but reported by Mother	Tree nuts Sesame Seeds Green Peas Soy	Hyperglycemia	No	No

Abbreviations: F – girl/woman, M – boy/man, ASD – Autism Spectrum Disorder, ADHD – Attention Deficit Hyperactive Disorder

EAI Information from Families with a FA

Parents, children, and youth were asked several questions about EAIs in their household and at school. All families reported having insurance which provided full or partial coverage for their EAI. It is unknown if participants who answered ‘Yes’ were fully or partially covered for their EAIs. One participant expanded beyond the answer ‘Yes’ and noted that their insurance

covered 75% of the costs and another parent stated during the interview that insurance covered 70% of the cost of the EAI. Annual EAI purchases ranged from 1–10, with an average of 3.8.

Most families (80%) opted to keep expired EpiPens in the house as backups, while two families (20%) opted not to retain expired EAIs. A summary of EAI information is provided in Table 5.

Table 5

EAI Information Summary

Child/ Youth by Age	Allergen	EAI (EpiPen) Carriage at School	EAI Insurance Coverage	Average Annual EAIs	Keep Expired EAIs	Stock EAI at School
8 (F)	Tree Nuts (Pistachio & Cashews)	1- on person	Yes	3	Yes, “just in case”	Unsure
8 (F)	Peanuts Tree Nuts (Cashew & Pistachio) Sesame Dairy Pink Fish	4- 1 on person, 1 in lunch kit, 1 in school bag, 1 at school office	Yes	5	Yes, “as back-up”	No
10 (M)	Peanuts Tree Nuts	3- 1 on person, 1 1 with teacher, 1 at school office	Yes	8-10	Yes, “just in case”	No
11 (M)	Peanuts Tree Nuts Seafood Eggs	2- 1 on person, 1 at school office	Yes	5-6	Yes, “just in case”	Unsure
12 (M)	Eggs	2- 1 on person or in bag, 1 at school office	Yes	2	Yes	No
14 (F)	Tree Nuts (Pistachios & Cashews)	2- 1 on person or in bag, 1 at school office	Yes	3	No	No
15 (F)	Peanuts Tree Nuts	2- 1 on person or in bag, 1 at school office	Yes	2-3	Yes	No
16 (M)	Peanuts Tree Nuts Seafood	1- Expired, waiting to fill prescription, but kept in backpack	Yes	1	No	Unsure
16 (M)	Peanuts	1- in backpack or hoodie	Yes	2	Yes, “as back-up”	Unsure
*10 (M), Mom answer	Tree nuts Sesame Seeds Green Peas Soy	2- 1 in classroom, 1 at school office	Yes (75% of cost)	4-6	Yes, “just in case”	Unsure

Abbreviations: F – girl/woman, M – boy/man

FA School Policy

Parents were asked if they were aware of FA policies at their child's school. All but one reported that their child's school had a nut-aware or nut-free school policy. One family did not indicate their school's FA policy on the demographic form; however, during the interview they clarified that, to their knowledge, the high school their child attended had no FA policies in place, but the elementary and middle schools previously attended had nut-free or nut-aware policies. Three families (33%) indicated that having a 'nut-free' or 'nut-aware' school policy was an important consideration for choice of school their child attended.

Ecomaps

Participants were invited to create an ecomap illustrating relationships and environments relevant to their FA experiences. Although guidelines were provided, families had flexibility in their design. Families were given the choice to create one family ecomap or individual ecomaps for the child, youth, and parents. A total of 16 ecomaps were completed. When both parents participated, one shared ecomap was submitted. One mother created an ecomap on behalf of her child who did not participate.

Participant Interviews

Participant interviews were conducted in person or via video conference. Two families (i.e., parents and child and parents and youth) and one youth chose to be interviewed in person for both interviews. One mother and youth had difficulty connecting to video conference on their mobile phone so requested a phone conversation which was accommodated. All other participants opted for a video conference using Zoom. A total of 16 hrs 17 min of interview data were audio-recorded across all participant groups, including 9 hrs 27 min with parents, 3 hrs 51 min with youth, and 2 hrs 59 min with children. See Table 6 for audio recording times which

provide context for the depth or richness of the data obtained from the two interviews per participant.

Table 6

Participant Interview Audio Recording Time

Participant Interview Audio Recording Time (minutes: seconds)			
Participant Number	Interview 1 Time	Interview 2 Time	Total Recording Time
P01 - Youth	33:43	21:42	55:42
P02 & P03- Parents	49:35	28:12	97:47
P04 - Youth	46:22	29:23	75:45
P05 - Youth	21:34	13:13	34:47
P06 & P07 - Parents	43:42	36:55	80:37
P08 - Child	33:16	30:07	63:23
P09 - Parent	52:30	76:25	128:55
P10 - Child	23:47	12:13	36:00
P11 & P12 - Parents	33:47	23:14	57:01
P13 - Parent	51:36	21:58	73:34
P14 - Child	12:22	16:33	28:55
P15 - Parent	29:27	25:01	54:28
P16 - Child	24:00	27:53	51:53
P17 - Parent	26:25	16:12	42:37
P18 - Youth	17:59	12:33	30:32
P19 - Parent	29:19	22:16	41:36
P20 - Parent	29:02	16:01	45:03
P21 - Youth	16:53	17:38	34:51

Chapter Summary

This chapter captured the participant family demographic characteristics, child and youth health profiles, and information about EAIs, school policy, ecomaps, and length of participant interviews. The data presented provides a contextual foundation for understanding lived experiences as it relates to FA presented in the next chapter. The following chapter presents the findings through the lens of van Manen's (2014) five existentials to reveal deeper meaning about the lived experiences of FA among children, youth, and their parents.

Chapter 6

Findings from Children and Youth with a FA, and Parents: Striving for Safety

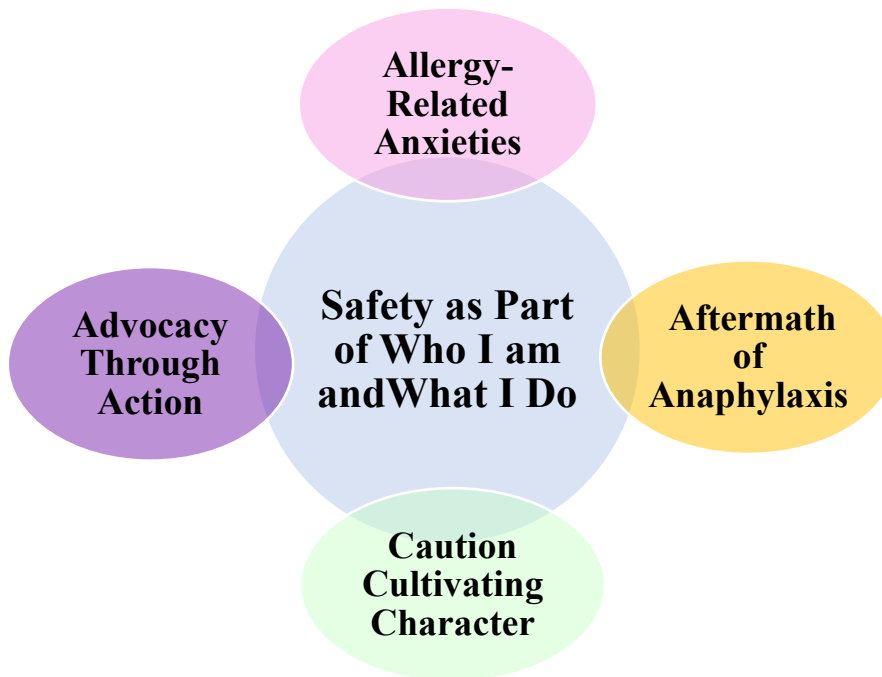
This chapter presents the findings from parents, children, and youth participants about their lived experiences of FA. The responses to research questions 1–4 as outlined in Chapter 1 (p. 9), are incorporated into van Manen’s (2014) five existentials of the lived experience: lived body (corporeality), lived relations (relationality), lived time (temporality), lived space (spatiality), and lived things (materiality). Within each existential, a core theme is introduced to convey the meaning which emerged from participant accounts of their experiences. Supporting subthemes are then explored to capture different facets of the theme with the intent to evoke a deeper meaning of the lived experience. Although the five existentials are used as a structural guide to present the findings, it is worth noting that overlap between each existential is inevitable and reflects the complex and interwoven nature of the lived experience. Further, while the research questions emphasized the school environment, participants consistently shared their lived experiences more broadly to include their everyday lives. The themes and subthemes therefore reflect this broader scope, illustrating the interconnectedness of the systems within the EST and demonstrate how these contexts may shape experiences at school. Following the presentation of the themes and subthemes, the overarching theme of the study is introduced to illuminate the holistic meaning and shared essence of their lived experiences. Table 7 (see below) provides a synthesized overview to guide the presentation of findings. The chapter concludes with insights and recommendations shared by children, youth, and parents regarding FA safety within the school environment. These recommendations directly address the fifth research question by capturing participants’ reflections on current school practices and their suggestions for enhancing school safety and inclusion.

Table 7*Striving for Safety: Existential Themes and Subthemes*

Overarching Theme: Striving for Safety		
Existential	Theme	Subthemes
Lived Body	Safety as Part of Who I am & What I Do	- Allergy-Related Anxieties - Aftermath of Anaphylaxis - Advocacy Through Action - Caution Cultivating Character
Lived Relations	Safety Through Communication & Understanding	- Value in Those Who ‘Get It’ - Evolving Acceptance - Setting the Tone at School
Lived Time	Seasons of Safety	- Emergence of Normal Over Time - Transitioning Responsibility - COVID-19: A Moment in Time
Lived Space	Holding Safety in Place	- Home Safe Home - Navigating Risk Landscapes
Lived Things	Living Safely Through Things	- Access to EAls - Food Labels: Reading Between the Lines - Digital-Based Support - Policy Essential Despite Limitations

Lived Body: Safety as Part of Who I am and What I Do

Lived body is the personal experience of one’s body within the world they live in (van Manen, 2016). The theme for lived body, *Safety as Part of Who I Am and What I Do*, encapsulates both the physical and emotional experiences of living with FA. It reflects how FA safety becomes forged as part of oneself, as does its required actions in all relationships, activities, and environments. Safety as part of who I am and what I do captures how safety becomes not merely an external practice, but an embodied way of being in the world for children and youth with a FA, and their parents. This theme is supported by the following subthemes which are explored further: *Allergy-Related Anxieties*, *Aftermath of Anaphylaxis*, *Advocacy Through Action*, and *Caution Cultivating Character*. A visual summary of the lived body is presented below (See Figure 1).

Figure 1*Lived Body***Allergy-Related Anxieties**

The subtheme, Allergy-Related Anxieties, captures the complex range of negative feelings that can arise from a real or perceived threat to safety from relationships or environments when living with a FA. These feelings are dynamic in that they may fluctuate over time and can vary in severity and/or duration as parents, children, and youth encounter different situations that can impact their perception of risk and threat to safety. Although these allergy-related anxieties (ARA) differed for each person, they appeared to be most bothersome for both parents and children or youth living with severe or multiple allergies.

Parents

Parents held a deep sense of responsibility for their child's safety and well-being, carrying the ongoing weight of managing risks and enacting preventative measures. ARA convey

the emotional experiences by parents as they navigated relationships and environments to mitigate risk and prevent allergen exposure. When parents were asked about what is like being a parent of a child or youth with a FA, they described a range of ARA that emerged at different points along their FA journey, rooted in a parental need to protect their child. Feelings of worry, anxiety, and stress were used to describe these experiences, particularly in situations that were perceived as real or potential threats to their child's safety.

Worry was a descriptor used by some parents to describe aspects of being a parent of a child with a FA such as constantly thinking about navigating the risks associated with FA and desire to keep their child safe from allergen exposure. Lynn, mother of male youth (12), spoke of having to always being concerned about cross-contamination when outside the home, "Yeah, the cross-contamination thing was a real worry when we were out" (P06, Interview 1). Andy, father of female (age 8), described the depth of worry changing from time of diagnosis to living with FA for several years, "where we are now, we are a lot less worried than when she was initially diagnosed" (P15, Interview 1). Martha, mother of male child (age 11), described her feelings that as a parent, you never stop worrying about their FA.

I don't think that, you know, even though he is becoming more responsible, it is something that will always be going to be in the back of my mind. It will be something I worry about even as he becomes an adult, because, I mean, accidents happen, right? (P11, Interview 2)

Anxiety is another term that was used by parents to describe negative feelings attached to the constant need to navigate the risks associated with FA in various environments. Ruby, mother of youth (age 14), described lasting anxiety as it relates to her daughter:

Yeah, there is still anxiety in relation to her allergy. And I don't know if that will ever go away. I would say for both of us. Again, probably less with her as she ages, but, you know, since she was two or three, that this has been a serious situation. So, it's in us to forever have our guard up on protecting her. (P02, Interview 1)

Parents also spoke about anxiety spikes at different times along their FA journey. Anxiety was noted as heightened during and after their child experiences anaphylaxis. Martha, mother of a child (age 11), describes the lingering anxiety she experienced after her son's most recent anaphylactic reaction which resulted in a hospital visit requiring multiple doses of epinephrine:

I think, to be honest, after that last experience [anaphylaxis], my anxiety has gone up. So, even just leaving him at home, or you know, for a few hours where, while me and my husband go out, you know, grocery shopping, even for dinner or something like that, I feel uneasy. (P11, Interview 1)

Similarly, Sandra, mother of child (age 10), described the anxiety she felt with the realization of the severity of her son's allergy after her son's first experience of anaphylaxis:

I'd say it [anxiety] was probably the worst, not after the initial diagnosis because I wasn't aware of the severity. But I would say after the epi-drip incident and after I missed, inadvertently gave him the wrong dose of immunotherapy, that was the highest then because it was the first time I realized the severity of it, like, how severe it could actually get. And the second time, it was something completely in my control. I think that has made me quite anxious. (P09, Interview 2)

Anxiety was described by parents at various points along their FA journey and was heightened with new or unfamiliar relationships, environments, or activities where food was present. The

experience of anaphylaxis also contributed to feelings of anxiety during and after their child's allergic reaction.

Stress was another common descriptor used by parents to describe what it was like to be a parent of a child or youth with a FA which was similar in tone to worry and anxiety. Stressful experiences described by parents focused on various activities and environments where safety could be in jeopardy or where parental control was minimal such as birthday parties, sporting events, or being exposed to allergens in school. John, father of male youth (12), described birthday parties as “super stressful” (P07 Interview 2), related to the foods served and the risks for cross-contamination. Further, in the school setting, his son was exposed to other students eating eggs in the classroom that put his son's safety in question. He felt that the school was focusing solely on nuts and not doing enough to be allergy inclusive which “caused me great stress” (P07, Interview 2). Tom, father of male child (age 11), spoke about the stress of leaving his son in the care of others and whether they would be capable and confident to give an EAI in case of an emergency:

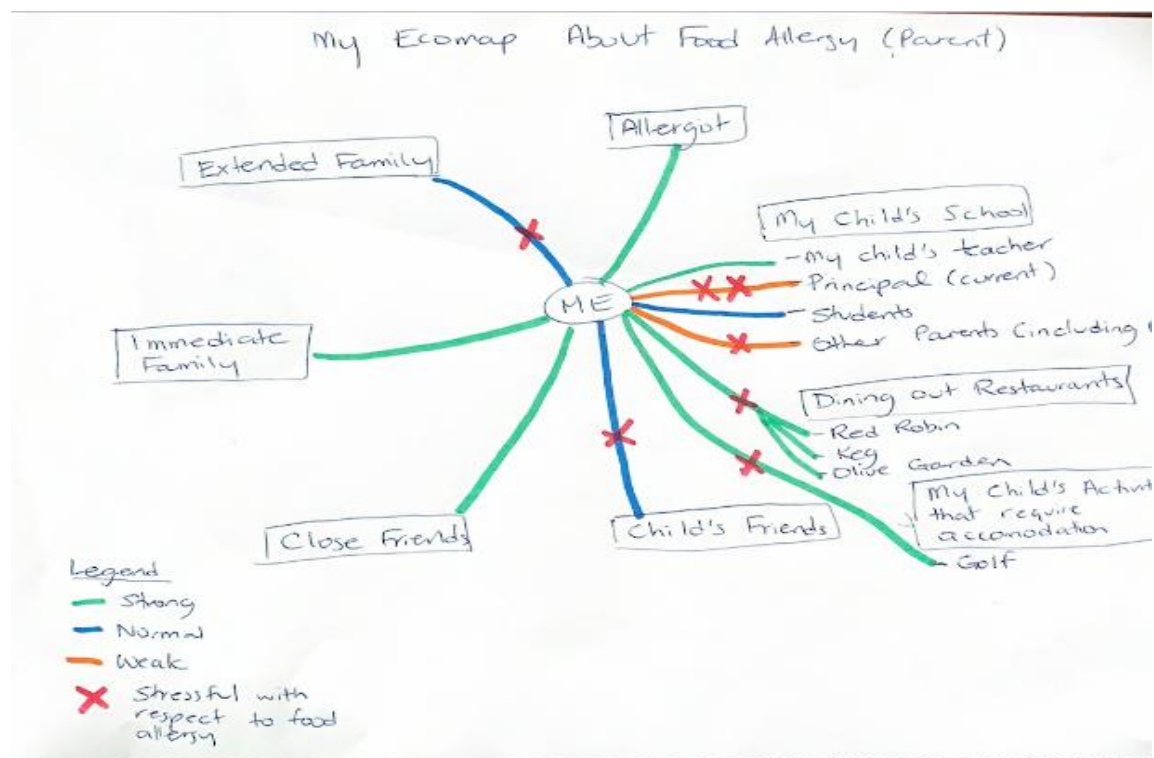
I think the biggest stress comes from when we leave him with his brothers. I am not confident that they would be able to do the EpiPen, if it was worst case scenario. They are very careful with him eating and we just tell him to wait until we get home and don't eat anything that you haven't had before. Because it's very hard to do it under stress, you can forget how. I just remember that blue to the sky rhyme and the visuals helped. That's always, always the stressor. And that's always in the back of my mind, like, will somebody be able to actually do it for him? (P12, Interview 1)

When Melissa, mother to a youth (age 16), was asked to describe what was stressful about being a parent of a youth with a FA, she found the limitations on food choices for her son as a source

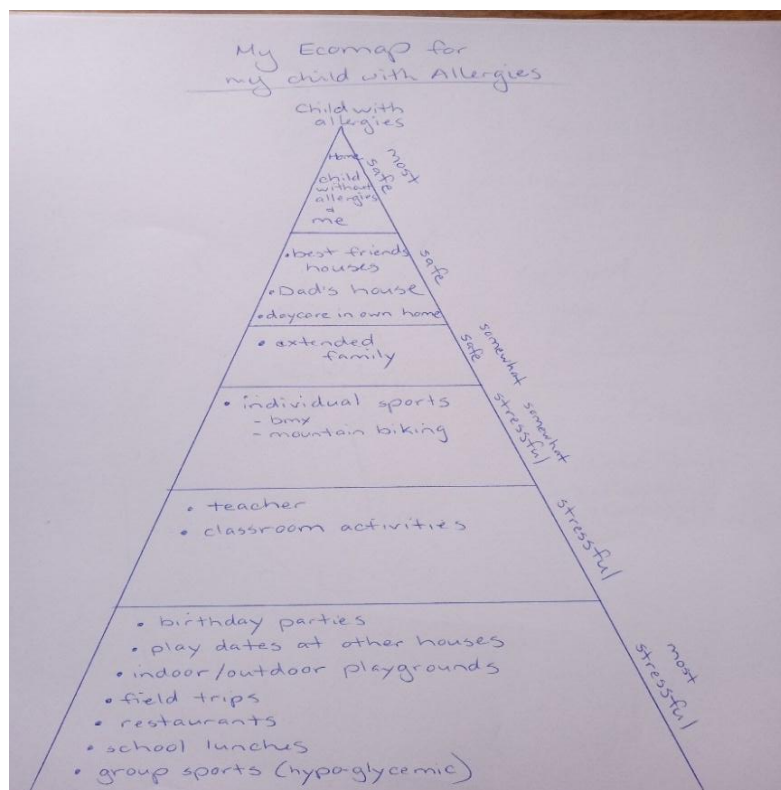
of stress, “Sometimes, we really want him to try some of the foods and we are not really sure what to give him, right? What to prepare for him...there is always limitations on food” (P20, Interview 2). Sarah, mother to a child (age 10) with multiple FAs, described the stress of a constant learning journey, always reading food labels, and the vigilance of planning activities outside the house.

Obviously, it’s stressful, there is a lot of knowledge that I have to keep on hand, and you continuously be on top of the game. It’s never research one and done kind of thing. It’s something you have to be aware of every single day, every single outing, every single activity. So, it’s very stressful in the sense where it’s a never-ending job. Um, you have to read every label, every ingredient, every single time, even if he’s eaten it a hundred times because you still have to read the ingredients list every single time. So, it becomes stressful in a sense where there is no, there is no ‘turning it off’, right? (P13, Interview 2)

Parent ecomaps depicted the various activities, environments, and relationships that can cause worry or stress in relation to their child’s FA. The ecomap created by Sandra highlights that even strong and normal relationships can be stressful in relation to her son’s peanut allergy (See Figure 2).

Figure 2*P09 Parent Ecomap*

Strong relationships with extended family and her son's friends were illustrated as stressful in relation to FA. Her son's activities that required accommodation regarding his FA was stressful, as was dining out at restaurants. Weak relationships with parents at school and at parent council were stressful for this parent, while the school principal was depicted as the most stressful in relation to her son's FA. Conversely, strong relationships included the immediate family, close friends, the allergist, and her son's teacher at school. Sarah, mother of a child (age 10) with multiple allergies, created a hierarchal style ecomap reflecting aspects of relationships, activities, and environments that were depicted as most safe to the most stressful (See Figure 3).

Figure 3*P13 Parent Ecomap*

Regarding stress, this ecomap depicts various relationships, activities, and environments that range from feeling somewhat stressful to the most stressful. When speaking about the ecomap, Sarah described that the stress felt was related to risk for allergen exposure during activities or when in certain environments where food is present and the risk for cross-contamination.

We found that when we were doing group sports, there was often, at the end of the game, shared oranges or shared cupcakes or Timbits somebody else would bring. And that became quite stressful for us. Not only did I need to make sure that the food around us was safe, but they weren't cross-contaminating anything. So, it was actually his [son's] personal decision, just to take up a lot of individual sports. He does mountain biking and that can be controlled a little bit easier. (P13, Interview 1)

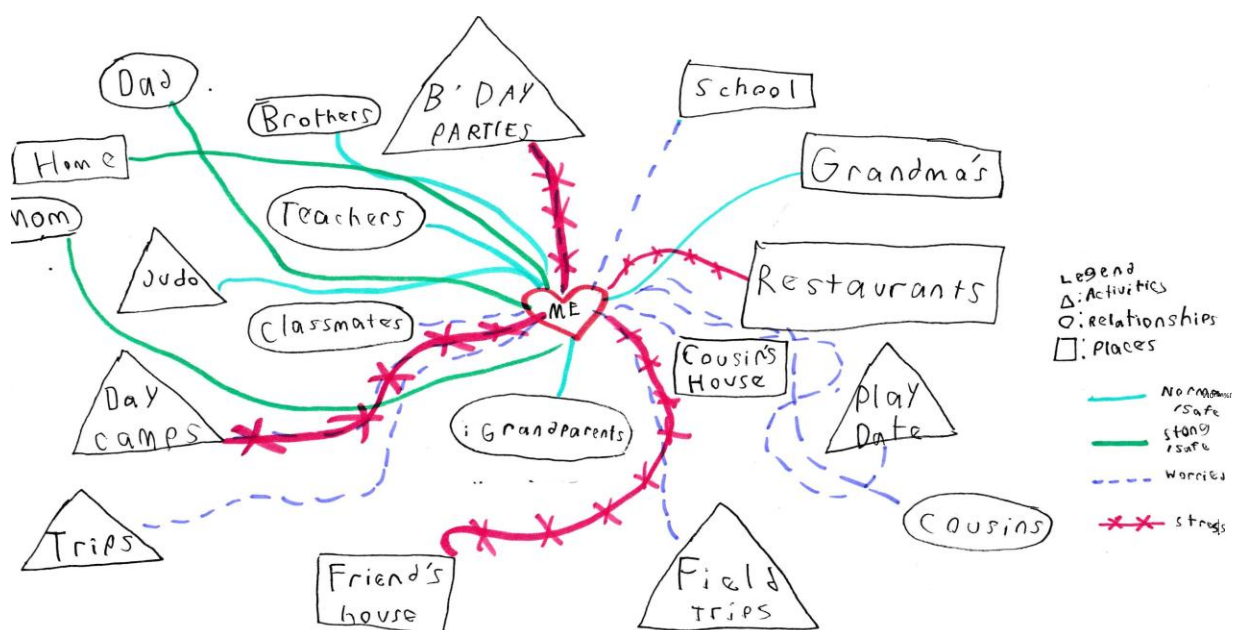
Children and Youth with a FA

Children and youth, like their parents, described a range of negative feelings when describing aspects of their lived experience related to their FA; however, differences in language were noted. Children or youth did express their feelings using similar descriptors such as stress and worry, but unlike their parents, did not use the word anxiety to describe their feelings in their ecomaps or interviews. Instead, feelings of concern, uncertainty, annoyance, and being uncomfortable or scared were articulated in various situations and are explored below.

Children and youth expressed their greatest worry was about having an allergic reaction and how to prevent its occurrence. All participants voiced varying degrees of stress and worry about certain relationships, activities, and spaces where safety could not be assured or was beyond their control. Liam (age 11), with multiple allergies, created an ecomap which highlighted his worry and stress with certain relationships, activities, and spaces (see Figure 4).

Figure 4

P10 Child Ecomap



Relationships that were worrisome, included classmates and cousins, as did activities outside the home such as playdates at classmates' homes, vacations, field trips, and attending school. For Liam, going to day camps, friends' houses, birthday parties, and restaurants were most stressful as it relates to his FA. When asked whether these were things he worried about every day, he responded, "Sometimes, yeah. Actually, I do". Further, in response to when he worries about things, he stated, 'kind of when I am at school or something and at home" (P10, Interview 1).

Worry and stress were common descriptors that were used by children and youth with a FA when discussing concerns about the presence of an allergen in their environment, cross-contamination, or having an allergic reaction in school. In school, Sally (age 8) with an allergy to cashews and pistachios, shared that she occasionally worried about having an allergic reaction at school despite the school's nut-free policy.

I am worried I am going to get an allergic reaction because, I am not worried all the time because you are not allowed nuts at the school or day care...I am not that worried, but sometimes my classmate's parents forget. I am thinking I am a little bit worried. (P14, Interview 1)

Another child Owen (age 10), with a severe allergy to peanuts, also used the terms worry and stress when thinking about his allergy generally and while at school. He denied any physical manifestations of worry; rather, describing it as thoughts in his head about the risks of cross-contamination and getting an allergic reaction. "It kind of stresses me before I go to sleep, but when I wake up in the morning, I don't stress about it, but then sometimes, it comes back" (P08, Interview 2). The presence of nuts at school caused worry about cross-contamination risks in that environment, "I can get worried at school, because sometimes, like, I don't know, I think some kids, not in my class, but in other classes, bring nuts" (P08, Interview1). "It's that [worry about

cross-contamination] and the fact that if, like, someone, is eating peanuts or who is walking past me, yeah, I could get an allergic reaction” (P08, Interview 2).

A general sense of worry about the safety of foods in relation to their FA was also described. Claire, with multiple FA (age 8), described worry as it pertained to food safety, “It’s not fun. Because, you always have to worry about food and it’s very, very, like, it just takes up time [worrying]” (P16, Interview 1). Trying new foods was particularly worrisome, “Well, what worries me the most is... Oh! Trying new foods”. Claire also worried about going back to the hospital, “Like, I worry because I don’t want to go to the hospital (P16, Interview 2).

For older youth living with a FA, present-day worries focused on the risks of food and the need to be prepared in environments outside the home. For example, when Darren (age 16), a high school student, was asked what was most worrying to him, he indicated that it was about always remembering to bring his EAI to school or other activities as an important safety aspect of living with food allergy “...not having my EpiPen. That would be about it” (P18, Interview 2). Another youth, Jack (age 16), with allergies to peanuts and seafood, created an ecomap using the terms stressful and uncertain as it relates to his FA to depict various environments such as school and other environments outside the home (See Figure 5).

Figure 5

P21 Youth Ecomap



Living with a FA was also associated with feelings of being uncomfortable or uncertain when interacting with unfamiliar people who may not understand FA as well as in environments where food safety was unclear. Katie (age 14) described being uncomfortable and having feelings of uncertainty at times as it related to her FA in environments outside the home such as going to friend's houses that didn't know her that well:

I didn't feel very safe if we ever had food around because not a lot of people understood my allergy, so a lot of those experiences made me stressful or worried sometimes. And at other friend's houses it was also very scary, and I got stressful because the parents... because their kids didn't have allergies, it was very hard for them to understand. (P01, Interview 1)

When Katie was asked to further describe her feelings around being uncomfortable, she stated "feeling uncomfortable would be really stressed, really worried, can't stop thinking about it, and like, just wanting it to go away type thing" (P01). Anna (age 15), with a peanut and tree nut allergy, described having safety concerns eating outside the home. For her, restaurants were mildly concerning, while foreign restaurants with a language barrier, bakeries, and food prepared by strangers (e.g., bake sales) were felt to be a major safety concern (P04, Interview 1). Jack (age 16) used the term stressful to characterize eating at restaurants and parties acknowledging that many foods may not be safe and where there is a lot of food present that may not be safe to consume thereby increasing his safety profile and risk of exposure.

Living with FA was described as an annoyance by three youth participants, a feeling rooted in the inconvenience and constant need to manage safety. Annoyance was related to not being able to eat certain foods, always having to read food labels, and having to self-carry an EAI at school or when high school students eating nuts in the classroom despite the school's nut-

aware policy. Cody stated, “It’s just, like, annoying because I can’t have them [foods that other kids can eat]” (P05, Interview 2), while Anna was annoyed at the constant safety checks required by one living with a FA, “Like, it’s sort of annoying, just, you need to check products and make sure you don’t eat something that is going to kill you” (P04, Interview 1). She elaborated:

My main annoyance, I would say, was when I was, like, in Junior School and Middle School, I had to wear an EpiPen around my waist which really annoyed me. That was my main, that was honestly the thing that bothered me the most. (P04, Interview 1)

Katie felt both scared and annoyed in her observation that students still brought nuts to school despite the school’s FA policy, “It didn’t make me feel comfortable. Even though it wasn’t the nuts I am allergic to, I feel for the people that do have the allergies to those things. And it’s like scary or annoying when people have nuts” (P01, Interview 1).

Children and youth identified a range of ARA that may arise while navigating FA in everyday life. Words used to describe these feelings included worry, stress, uncertainty, feeling annoyed, or feeling uncomfortable, particularly in unfamiliar situations or environments where food may be present and safety felt uncertain. These feelings were also used to describe experiences related to making decisions about food safety with others who were perceived to less familiar with their FA. For many, this required making ongoing judgements about who could be trusted to understand and manage their FA safety.

Aftermath of Anaphylaxis

The subtheme, Aftermath of Anaphylaxis, refers to the enduring psychological impact of experiencing anaphylaxis, a threat to physical safety, and how such experiences shape subsequent feelings and actions around FA safety and management. Anaphylaxis represents not only a medical emergency that threatens the physical body, but symbolizes a breach in safety that

parents, children, and youth strive for in their daily lives. Participants describe the aftermath of their experiences and how it shapes their identity. This subtheme explores these experiences from parent reflections and first-hand accounts from the children or youth in this study who have experienced anaphylaxis.

Parents

Parents described the fear and other emotions felt witnessing their child experience anaphylaxis and how these frightening moments impact their psychological state and reshaped their approach to FA management. Melissa, mother of male (age 16), recounted rushing their child to the hospital after eating a chocolate which contained peanut butter at a family event at a park. She described the experience as “Very scary. Very scary because his life [was at risk]” (P20, Interview 1). She later described feeling angry that nuts, a snack which she regularly enjoyed, had put her son’s life in jeopardy. “I throw it out [nuts in the house]. I was so mad, like, it almost killed my son, you know? I had to get rid of that. So, now, it's in my locker at work” (P20, Interview 1).

In addition to the fear in the immediate experience of anaphylaxis, parents recalled their experiences afterward. Martha and Tom, parents of child (age 11), describe heightened feelings of anxiety and worry, becoming hypervigilant about safety in the aftermath of their son’s most recent experience with anaphylaxis. After an accidental ingestion of a peanut M & M, their son required the administration of epinephrine at home with an EpiPen and again by hospital staff. Tom stated, “I mean we; we prepare as much as we can, but nothing really prepares you, like experiencing it, and going through it, and how, how scary it is” (P12, Interview 1). Martha spoke of her increased anxiety about FA after that their son’s experience with anaphylaxis. She also described a heightened awareness by herself and all members of the family:

I think after experiencing that, like, all of us, because all of us were here, I think our eyes are a little bit more open and are more careful again with you [husband] mentioning how quickly it can happen and turn into a life and death situation. (P11, Interview 1)

Lynn and John recounted their feelings following an incident in which a parent volunteer gave their son with an allergy to eggs, a snack at a school summer camp resulting in an anaphylactic reaction requiring multiple doses of epinephrine and transport by ambulance to the hospital, which Lynn characterized as “horrifying” (P06, Interview 1).

We tried not to be vengeful and ‘get them’. Yeah, they felt terrible. Again, luckily, he was fine. It was just a parent volunteer. I am pretty sure a different outcome would have changed our sentiment. It really sucked that it happened. And he went back to the camp, and he went back to the camp the next day. (P06 and P07, Interview 1)

Lynn also described the guilt she felt in the aftermath of her son’s first anaphylactic experience.

And then because I fed him, you know, afterwards, I felt horrible, right? Because, like, I put him through this, like, traumatic experience and then for our family being in the hospital with him. I knew there were some allergen foods, but I didn’t know eggs was a big deal, right? And, not educated enough about potential allergens. (P06, Interview 1)

For parents, anaphylaxis is a defining moment that leaves them grappling with their emotions, serves as a reminder about their child’s physical vulnerability, and reinforces the commitment to hypervigilance to maintain a sense of safety.

Parents also described their observations of how anaphylaxis impacted their child. Tom shared how anaphylaxis affected his son’s anxiety and sense of preparedness.

After the incident, his anxiety levels were high and he was very...what’s the word I am looking for? Paranoid. Yes, that’s the word. He’s very scared that it might happen again,

so he will take extra caution, reading every package of food you eat, all the ingredients, and he doesn't want to take any risks. (P12, Interview 1)

That said, Martha and Tom reflected that although stressful, the experience could be beneficial in the long term by preparing him with what to expect with the hope that he would be able to take quick action in the event of a future reaction.

I think him being exposed to that stress already has helped because, because it happened twice already, I think he kind of knows what to expect. So, I am hoping if there is a third time, he wouldn't be in such a panicked state. He would have more of a 'Okay, I have to do this in order for me to live'. So, I think that helps us too. Luckily, he survived it, but surviving has made him, well, he has learned from that experience. Part of that fear contributes to him being very meticulous when checking the ingredients and stuff. Like, he knows this is survivable and what he has to do. Whereas before, he would freak out and say, 'I don't want to die'. Or even be afraid to use the EpiPen, to use the EpiPen he would be terrified to do that, but now he feels comfortable, like, he knows he'll need to use it. (P11 and P12 Interview)

John and Lynn also expressed that while traumatic, experiencing anaphylaxis contributed to a valuable understanding of symptom recognition and renewed vigilance. Lynn highlighted this sentiment by expressing:

A year and a half ago, he had the anaphylactic reaction at the allergist. And as bad as it was, in a way, it's good that he did have it, because now he knows the signs and symptoms, and he got through it with an EpiPen in the office. Now, that has made him more vigilant again. He did not like that and does not want to have a reaction and be poked again (P06, Interview 1)

Parents in this study whose child experienced anaphylaxis described the event as scary, horrifying, and frightening. In its aftermath, parents describe heightened anxiety and hypervigilance on their part and that of their child or youth in attempts to regain control and a sense of safety in their lifeworld. Some parents also share that there are lasting imprints on the self of their children impacting their psychological well-being.

Children and Youth

Children and youth who have experienced anaphylaxis, like their parents, expressed their fears and emotions, as well as describing the impact on the physical body. Those who could recall anaphylaxis described their physical symptoms, thoughts about receiving an EpiPen, and going in the ambulance and/or the hospital in a matter-of-fact tone. Claire (age 8) recalled drinking milk at a young age and having to have an EpiPen in the ambulance or at the hospital and being accompanied by her parents. Owen (age 10) described his physical experience of anaphylaxis, “Yeah, I think I was really hot. I kind of fainted on the couch. Like, I blacked out. Yeah. I vomited and then I blacked out” (P08, Interview 1). Owen described receiving an EpiPen administered by his mother, “It hurts a little, like, when the needles goes in, but other than that it is fine. And I don’t think any blood comes out”. Liam (age 12) also described the physical experience of anaphylaxis “It’s kind of scary, when I have an allergic [reaction]. Because when I accidentally eat something, it causes me, like, a swollen tongue and hives” (P10, Interview 1). His mom asked him if it was scary and he responded, “Yeah, I don’t want to go back to the hospital” (P10). He recalled two experiences with anaphylaxis:

So, the first reaction was, like, I ate some sort of cucumber with some kind of sauce, hummus sauce. And my lips started to get swollen and started to change colour. Then we rushed to the hospital and then we used the EpiPen and then rushed to the hospital. [The

second time], I ate those, like, small M & M's in the tube. And I ate a few of them. And then my tongue started to get funny, and I noticed on the container it said peanut butter. I felt a swollen tongue and then I threw up. And then right after I had to use the EpiPen and then I suddenly got a swollen throat. Then, I went to the hospital, and I got two shots. I kind of threw up and had diarrhea. Um, my fears were, I didn't want to die. (P10, Interview 1)

Children also described the physical pain associated with needles after receiving an EAI when experiencing anaphylaxis. Claire (age 8) stated:

I didn't like it. That's because I'm just a little kid! And that's why I don't like needles! I don't think they [EpiPens] hurt, but I only think the part that hurts is when they put it to your thigh, because there is a little button thing and the thing, like, they, like, do it hard! Then, and then, the hard part smashes against this part [shows part of her leg]. (P16, Interview 1)

Cody (age 12) described forgetting about the physical symptoms of anaphylaxis due to the fear of the EAI, "I am sort of nervous to have it, the shot, like, I kind of forgot about my throat" (P05, Interview 1). Cody differentiated between the small needle at the hospital versus the EAI injections, with the smaller needle being better tolerated, "Well, like, I wasn't really scared of the shot, like a COVID shot or something, but, I don't like, I don't like this one [points to leg] because its...yeah, it just hurts" (P05, Interview 1).

Youth who were too young to recall anaphylaxis or who have not yet experienced anaphylaxis also shared their thoughts. Although Darren (age 16) has no memory of his experience with anaphylaxis because it happened at very young age, the knowledge that it did happen has shaped his approach to allergy management and vigilance.

I had my first allergic reaction when I was, like, one or two. I never actually knew what it would feel like. So, just I always felt concerned that I didn't want to. I just knew it would be bad. And so, I didn't want to trigger it at all. (P18, Interview 2)

Katie never required the use of an EAI but has been taught regularly how to use one with the EpiPen trainers. She expressed her fears about having to give herself an EAI injection in the event of an anaphylaxis emergency:

I was always taught how to use it, like, with practice ones. I made sure I knew how to use it, how to do the 'blue to the sky, orange to the thigh.' But, I feel like in the moment I would probably freak out a little bit and not want to [give injection] and be really scared because it was told to me that it's a really scary moment...Now, if I ever have to use one, I probably, I would still feel scared but it would be a little easier as you get older...just the fact that having something stabbed into you and you are going to, you, might die because of it if you don't. It's pretty scary. (P01, Interview 1)

One child expressed a fear of dying because of having multiple FA and experiencing anaphylaxis. Liam (age 11) alluded to his fear of death in stating, "I just don't want to, like, die from an allergic reaction (P10, Interview 1). As a result of these fears and his most recent experience with anaphylaxis, his parents shared that their son was experiencing increased anxiety. They also observed that he was taking extra precautions and was hypervigilant in checking all food labels and carrying his EAI, noting the lasting impact of anaphylaxis.

Advocacy Through Action

The third subtheme for lived body, Advocacy Through Action, captures how parents, children, and youth are compelled to be active agents in creating safe relationships and environments in their world. All are thrust into taking on the role of advocate with the purpose of

teaching others, mitigating risks, and minimizing allergen exposure, all while promoting allergen safety and inclusion.

Parents

Parents are thrust into a role of advocacy on behalf of their child from the time of diagnosis, a role that continues throughout their child's FA journey. Advocacy in action takes on many forms such as raising awareness through education of family and schools, communicating with teachers, parents, and manufacturers about the safety of their products, or volunteering at school to help ensure a visible presence and engaged voice for FA safety in their child's school.

Advocacy Through Action for parents involves not only communicating about their child's allergy but also providing education around FA safety to those within their child's environment from grandparents, other parents, and school staff. Educating extended family, in particular grandparents, about FA safety, risks of cross-contamination, and how to use and EAI was easier for some families than others. Nicole, mother of son (age 16), shared that a considerable effort was made by herself and husband educating grandparents about FA safety and caused some initial concerns leaving their sons in their care:

And getting the parents[grandparents] on board was a little harder. They just thought that, you know, if we're not eating it when they're not here, it's okay. But, not realizing that, you know, sticking your knife into a peanut butter jar and then into the margarine pot and then using the margarine for the boys, it's still the same thing because there's cross-contamination. So, that was kind of hard to get through. We had to remind the parents a lot because we'd be over there visiting, and they'd be sitting at the table putting peanut butter on their toast. So, sometimes we just left the situation and, but eventually they just got better and there'd be lots of reminders or they'd start asking us, like, 'Can I make this

or that baking if it is a ‘may contain?’ and it got better definitely over time. (P19, Interview 1)

Nicole further elaborated about educating grandparents in the following excerpt:

We had a trainer EpiPen, we had both the Allerject and the EpiPen version, so we showed them all how it worked and practice on the little trainers. I think it was harder on the parents because they didn’t have a lot of experience with FA with none of us having grown up with any of it. But, just telling the more about the cross-contamination, like, ‘Your grandkids are sitting at the table, please don’t put peanut butter on your toast’ type thing. And it did take some time and during that time we didn’t feel safe leaving the kids with them until, they kind of, had a better handle on it. So, when the grandparents realized ‘Oh hey, we are not going to get sleepovers with the kids until we, kind of, get on board with this,’ then it happened a lot quicker. (P19, Interview 2)

Lynn and John shared that a lot of education and reinforcement was necessary with Lynn’s parents. They suspected this was because they lived far away and was not part of their daily routines. Lynn stated, “We had to do a lot more education with them and remind them...probably because of geography and daily occurrence, not living close by” (P06, Interview). John shared that leaving their son in their care in the early years, they both felt “petrified” (P07, Interview 1). In contrast, for Andy’s family, getting extended family members on board was a smooth process, “We didn’t get any push back from anybody”. After he and his wife took a course from their local allergy clinic to educate themselves, he mentioned “And actually, my mom took a separate course too, just for herself, to be a support to the family” (P15, Interview 1).

Advocacy also took the form of pre-emptively seeking detailed information to ensure greater certainty about what their child could safely eat.

Behind the scenes, also just calling food companies. If I am never sure, even prior to going to a birthday party, I would text a mom and say, ‘Where are you getting pizza from?’ or ‘Where is your cake from?’ and doing my own background research to send her confidently to have fun at the birthday party. So, calling companies, speaking to restaurants...it’s time, it’s work, it’s talking to the teacher, trying not to be a burden, and I often felt like I was a burden. (P02, Interview 2)

Similarly, Sandra, mother to a son with a severe peanut allergy, communicated with various food companies to find out first-hand about allergen content and safety. She shared, “If it is a new product, after I call them, I usually correspondence by email, then we let him try it” (P08, Interview 1). This type of advocacy work was often done automatically, and children were not necessarily aware of the all the behind-the-scenes advocacy work that was done on their behalf to keep their child not only safe but feeling normal and included in their environments.

Advocacy through communication with the school about their child’s allergy was also evident in the participant interviews. Lynn, mother of son (12), emphasized her advocacy with the schools, “We definitely try hard to advocate, right? Like, every principal we let know, every teacher, every flight, you let everyone know” (P06, Interview 1). Advocating for their son in school was reiterated by her husband, John, “We were quite clear. We were quite strong advocates” (P07, Interview 1).

School volunteer was a role parents, particularly mothers, took on as part of advocacy through action. The role of school volunteer included working the hot lunch program, lunch monitor, and/or sitting on parent advisory committees (PAC). Sandra, whose son is severely

allergic to peanuts, is active within her child's school. She stated, "I sit on the hot lunch committee even though neither of my children eat hot lunch, just so I can make sure I have input on what vendors we bring in" (P09, Interview 1). She also shared:

Relationships are reciprocal, right? Like, if your principal is really good to your kid, you do whatever you can to support them. I fundraise for them, organized a lot of events, involved with PAC, so I got to know him better. And then I think that they, it was just easier to get his ear, to make sure my son was kept safe, right? (P09, Interview 1)

Ruby, mother to daughter (14), stated, "I volunteered in another public elementary school, as a noon-hour supervisor, so I kind of got to see behind the scenes on how that school deals with [allergy]" (P02, Interview 1). Nicole also volunteered at her son's school starting in the early years and continued through high school:

They did do bake sales at school, so I was always a part of that. They were in kindergarten until they left school, and now I'm also on, at the high school Parent Advisory Council now because you just want to get as much background information as possible. (P19, Interview 1)

While the roles parents took on as volunteers in their child's school varied, their involvement was driven by the need to assess safety within the school environment and allowed an opportunity to advocate for safe practices if required to principals, teachers, and other parents within the school environment.

Children and Youth

For children and youth, Advocacy Through Action, focuses on self-advocacy demonstrated by educating and communicating with others about their FA, and as well, by taking precautionary measures such as reading labels and having access to an EAI. From an early age,

children and youth have been taught to speak up about their FA as an important safety measure and becomes part of their embodied self. Speaking up about FA took on different forms including informing restaurant staff of their FA, providing reminders to their peers about not bringing nut products to class, and educating others about their FA and FA safety.

Self-advocacy was evident at all ages, even amongst the youngest participants. In the school environment, two children described how they advocate for themselves by reminding others of school policies. Owen (age 10) described talking to teachers and classmates about FA safety and reminds them not to bring nuts into the classroom, “I basically said, ‘I have allergies and if you have any peanuts or tree nuts in your food, tell the teacher and go outside to eat it. And then, also, tell your parents not to pack it’” (P08, Interview 2). Claire talked about reminding her class to wash their hands, “I want them [other students] to know that if they are having food, then they need to wash their hands because then I will be safer” (P16, Interview 1). She went on to share, “I need to remember to remind people that I have FAs because otherwise they will not, they will not know and then maybe get me sick” (P16 Interview 2). Another child, Sally (age 8) provided education to other students when asked what about the EAI around her waist, “Most people ask me why I am wearing my EpiPen and what it does. So, I tell them what it does and why I need it” (P14, Interview 2).

Youth participants described self-advocacy through speaking up for themselves, remembering to ask others (e.g., restaurants) about potential allergens, and being cautious around food in general. Darren (age 16) shared that FA safety is embedded into his everyday routine:

It’s the kind of thing where if anybody offers me food then, like, it kick starts in my brain again and I just go through the process of the, like, ask a question if it’s not trusted or can you immediately identify it has [peanuts] or not? (P18, Interview 1)

Restaurants were settings where youth frequently practiced self-advocacy by informing servers of their FA and inquiring about safe food options. Darren explained:

Yeah, restaurants are the main place I would ask if it contains peanuts. I feel obligated to double check to make sure, like, I always have my EpiPen when I go to all the restaurants. But I guess I just, I'd much rather not use my pen and just ask. (P18, Interview 1)

Anna (age 15) also spoke about self-advocacy in relation to communicating with restaurant staff about her allergy:

One thing that is positive that came from the experience is being better at advocating for myself, uh, this is mainly in restaurants or, yes, just places that serve food. I'm a bit more confident in advocating for myself. (P04, Interview 2)

Safety precautions within the school environment such as not sharing food and moving away in the presence of allergens were also noted. Darren (age 16) stated that even as a young age he knew not to share food at school, "Even when I was younger, they offered me food [with peanuts] and I was educated enough to know just not to take it" (P18, Interview 1). Cody (age 12), who has an allergy to eggs described how he responded if he noticed eggs at school during lunch, "It was just a little bit uncomfortable, but I just moved away" (P05, Interview 1).

Similarly, Jake (age 16) stated that if he noticed nuts or seafood at school, "I would probably move away or tell them about my allergies, just so they are careful" (P21, Interview 2). Jake also shared that he avoided risks while eating out to ensure his safety. He noted, "I just don't order anything that would be, like, um, like a risk for my allergies" (P21 Interview 1). His advocacy was also evident in his advice to others with a FA:

Just be aware of everything, like, even if it's safe, even if it's dangerous, you just have to be really aware of your surroundings, especially around food. You can't be really caught off guard, since it could risk your life and stuff. So, you have to be careful around everything. That's why I bring a lot of snacks from home. I don't even have to take food from others. (P21 Interview 1)

The above excerpts provide examples of Advocacy Through Action for children and youth who continually orient their actions to minimize risks and preserve their sense of safety while at school, at a friend's house, or at a restaurant.

Advocacy Through Action was also demonstrated among participants through the practice of reading food labels. All child and youth participants spoke about checking food labels as an important part of FA safety. For younger children, it was understood that checking labels was important, but it was not yet an independent skill and would defer to their parents or a trusted adult for reassurance of safety. Sally (age 8) stated "My parents will check the ingredients" (P14, Interview 2). Claire (age 8) also indicated, "Every time I eat food, I need to read the ingredients" (P16, Interview 1). For older children and youth, reading food labels was ingrained in their routine and provided them with a reassurance of safety. When asked if reading food labels made her feel more comfortable, Katie (age 14) responded:

Yeah, it really did. I remember at my best friend's house on time, we were going to eat grilled fish, and obviously its fine, but they [her parents] taught me how to read the label and look at the 'may contain' and which really helps me now too, like, I understand when checking things. That was really helpful, to know how to read it myself, so I knew personally that it was okay, because sometimes people don't know how to check labels

either. Like, I didn't know until I got taught, so me checking really helped me feel more comfortable. (P01, Interview 1)

Jack also succinctly stated, "I just read every label. Like, if I buy food from a market, I would always read the labels before eating it" (P21 Interview 1). All children and youth understood that reading food labels was central to FA safety, with younger children relying on parents to check or double-check foods and older participants doing so independently.

Self-advocacy for all participants in this study included learning about EpiPens and remembering to always bring their EpiPen to school or other activities. The following excerpts demonstrate the importance of carrying it on person to feel safe. At school, Katie shared:

It's always in my backpack which I carry around with me from class to class. Sometimes, the odd time, I might not have one, but if I am going out somewhere, to a restaurant or a mall or something, I will always have one with me in my bag just in case. Or in school, there is always one in the office. (P01, Interview 1)

Anna (age 15) carried her EpiPen on person, "I carry an EpiPen, usually on me in a pocket or in my school bag" (P04 Interview 1) as did Jack (age 16), "I always just kept it in my bag" (P21, Interview 2). Darren stated, "I always have an EpiPen, either on my person or in, like, a bag. So, I'm not really ever concerned" (P18, Interview 1). Again, having EAI was part of the daily routine and helped preserve a sense of safety at school and other environments.

Caution Cultivating Character

The fourth subtheme, Caution Cultivating Character, refers to how the lived experiences of FA can shape positive character growth in children and youth. In learning to navigate the daily demands of FA safety, responsibility, resilience, patience, and advocacy skills can emerge. Parents did not describe their own character growth, rather emphasized their observations of their

child. Therefore, this section will focus on parent accounts of their child and as well, perspectives from children and youth participants.

Parent Perspectives About Their Child

Parents were asked to reflect on positive aspects of their child's character growth and development because of living with a FA. Thoughtful consideration by parents revealed that both children and youth embodied character traits such being responsible, patient, and resilient all of which are shaped by continually having to seek safety and navigate daily risks. Children or youth with a FA were described by their parents as responsible, careful, and cautious as it related to their FA. For Sarah, she teared up with pride reflecting on the development of her son's (age 10) responsibility, "Overall, I am most impressed with how responsible and mature he is – he is exceedingly responsible" (P09, Interview 1). Tom and Martha described their son (age 11) growing a sense of responsibility after experiencing anaphylaxis and as part of getting older, with Tom stating:

He's just really careful. Like, yeah, he's older now, so he has more responsibility. He is more self-reliant, so he always knows where his medicine is and um, we have kind of trained him to...out of the blue where we will just say 'Where is your bag?' and just always saying that you always have to know where it is, so and he kind of trains [brother] a bit and [brother] is pretty responsible and [oldest brother] is too, so I think it is getting better now that he is older (P12, Interview 2)

He further when on to describe his son's increased responsibility for his own safety:

He is showing a lot of responsibility. He is very cognizant of too, if there is, even food items that have, like, a peanut free symbol on it, he will still read the back of the ingredients. So, I

think the incident (anaphylaxis), kind of, you know, made him a little bit more aware and responsible to what he is putting in his mouth. (P12, Interview 2)

Being cautious about decisions around food choices was also described as a positive attribute developed from FA and tied to responsibility. Lynn stated:

He's really, really cautious. Like, even when we have something new at home that says it has eggs in it, like, right now we have cream puffs, like, with egg. He won't have them because he hasn't had them before. He doesn't want to have it at night. He's like, really rigid and cautious. (P06, Interview 2)

In addition to being cautious, being a rule-follower, was also a helpful character attribute that developed as a result of living with a FA. Lynn described how being a child that followed the rules facilitated parenting a child with a FA as it allowed parents to gain trust that their child would make safe decision about safety based on their family rules about FA when at school or away from home. During the interview, she spoke directly to her son, "Like, you always, like, were a rule-follower. So, if me and Dad said something, you did it. But there is a lot of kids who don't pay attention, or like, don't have the ability to make good decisions" (P06, Interview 1). Andy, father of a child with a nut allergy, also described being a rule-follower as an embodied part of his daughter (age 8):

She is, like, her personality is like a rule-follower. So, the rule is, like, have her EpiPen. I am more likely to mess up than she is. But I don't think that she, like, pictures having an allergic reaction in her head and what would happen. I think it is more of the rules and don't have cashews and pistachios and it's more of like 'I don't want to break the rule', right? (P15, Interview 1)

Patience and delayed gratification were other positive character attributes that has developed in their children through living with FA. Lynn, mother of child (age 11), described receiving treats at school and waiting to get home until it was checked as safe. “I am really surprised at his willpower to wait until he gets home to have something. So, it’s taught him will power and patience. He will just play it safe” (P06, Interview 2). Melissa, mother of a youth (age 16), also spoke of her son’s patience and delayed gratification when receiving a treat when at school or from a friend:

We always tell him, like, make sure to not eat it yet until you get home. Like, just the candies and chocolates to make sure it’s good [safe] for you. He’s really, very, you know, he remembers when he was younger so that’s what he’d do (P20, Interview 2)

Sandra provided another example of delayed gratification, describing how her son’s ability to resist treats will be beneficial for him as he gets older, indicating:

It’s like, I know he will resist the pressures of teenage years when kids come around with drugs and all of these other things, he will be able to say ‘NO’. And his ability to delay gratification is bar none, like, he can, forego whatever the treat is. Like all of these kids are, like, stuffing their faces with it and he is able not to have that. And it is translating into his academics and, like, whatever stuff he does. He is so amazing in that way, you know? I think I have a lot of pride in that. (P09, Interview 1)

Patience and delayed gratification, observed by parents, was not only was helpful in managing risk and enhancing safety, but also were also described as attributes that would be beneficial in all aspects of their life.

Finally, when asked about how FA has shaped the growth of their child, some parents described their child’s resilience. Ruby stated, “Resilient, definitely, I think it has made her a

much stronger, aware individual. She can't just flutter through life, she has to be 'on', and always paying attention (P02, Interview 2). Sandra described her observations of her son (age 10) and others living with FA, "I think people will tend to think people with food allergies have, they have this negative perception of them, but people with food allergies are very resilient. They are mentally strong, emotionally strong, and they plan ahead" (P09, Interview 1).

Parents shared their perspectives about their child's positive character growth from living with a FA. These included becoming responsible, cautious, resilient, patient and empathetic. Pride in their child was evident in their choice of words and some parents demonstrated this with emotion (e.g., getting teary-eyed). Not only were these attributes reflected on with pride, but they also helped foster a sense of trust that their child would navigate their world with safety and caution in mind while at school or other environments.

Children and Youth

Children and youth's perspectives on the positive impact living with a FA had on their character development was described somewhat by children and youth. Instead, the positive impact on their character was demonstrated in how they described confidently managing their FA in their daily lives through communication and self-advocacy such as speaking up for themselves about their allergy, reading food labels, and diligently carrying their EAI.

Youth described themselves as comfortable, confident, and resilient as it related to their FA. As a youth reflecting back on growing up with a FA in school, Anna (age 15) described building her resilience through learning you could not always have or get what you wanted as a child, "Like some experiences, where I just couldn't have something I wanted, but, especially when I was younger, it helped me learn to get over it in a way, or yeah, build more resilience" (P04, Interview 2).

Children and youth also spoke of developing advocacy skills and confidence with communication. Anna (age 14) described developing self-advocacy skills and her confidence in communication at school and in restaurants as a positive aspect of having had to live with a FA:

One thing that is positive that came from the experience is being better at advocating for myself, this is mainly in restaurants or, yes, just places that serve food. I'm a bit more confident in advocating for myself. So, just better at asking for what I want. It actually made it a bit easier to communicate with my teachers as well. You know how when asking a restaurant worker for accommodations, you were talking to a person who is in power or in some sort of power in that situation. So, I got a bit better at talking to authority figures in a way. (P04, Interview 2).

Katie (age 14) also spoke about communication and how living with FA impacts self-development. She described:

It kind of shapes you as a person, so like, you learn how to do so much more different things, and how to feel comfortable in different places. So, you can, like, speak up for yourself, now how to communicate better with people, [and] different things like that. (P01, Interview 1)

Self-advocacy and confident communication at school were also demonstrated by Owen (age 10) when his teacher asked him to speak to the class about his allergy. Owen stated, "Mostly [I said] my allergy was this, and not to bring peanuts and tree nuts into the classroom. And to the parents that make the lunch, not to put it [allergen] in" (P08, Interview 1).

Parents described their children as responsible. Although children or youth did not describe themselves as responsible per say, it was demonstrated through their actions around food allergy safety and management at school and other environments. Actions showing

responsibility included checking products for food safety with trusted adults, reading food labels consistently and independently, practicing using an EAI trainer, and having access to their EAI at school or when outside the home. When Owen (age 10) was asked about what it was like to have a FA, his response summarized actions demonstrating responsibility in this way:

It is kind of difficult. You have to search for foods because you have to check. Like, if you go to a restaurant, you have to check with the restaurant, and then you also got to carry an EpiPen with you. And then you have to read the ingredients on everything you eat! (P08, Interview 1)

Although not always described explicitly, children and youth demonstrated character growth from their experiences living with a FA was reflected in their daily management of FA.

Lived Relations: Safety through Communication and Understanding

Lived relations, is an existential which explores how individuals experience and make meaning of their relationships with others in the world (van Manen, 2016). The theme which emerged for lived relations is, *Safety Through Communication and Understanding*. This theme reflects how children and youth with a FA, and their parents, come to feel safe, understood, and supported when those around them communicate awareness and knowledge of FA and demonstrate a commitment to safety, fostering a sense of trust and connection. Three subthemes that support this theme: *Value in Those Who 'Get It,' Evolving Acceptance*, and *Setting the Tone at School*. All three subthemes will be explored below in support of the theme for lived relationships, safety through communication and connection (See Figure 6).

Figure 6*Lived Relations***Value in Those Who ‘Get it’**

The first subtheme, Value in Those Who ‘Get it,’ reflects the invaluable relationships of family, friends, teachers, and other community members when efforts are made to understand FA and support is demonstrated through informed communication and thoughtful actions. This subtheme also reflects the gratitude, appreciation, and positive feelings around those taking the time or going out of the way to make parents, children or youth with a FA feel safe and included through communication and actions fostering a sense of connection and trust. Conversely, this subtheme also captures the impact on families from those who ‘don’t get it’ highlighting the relational differences that shape the experiences of living with a FA.

Parents

Parents of children with a FA expressed feelings of safety, comfort, and connection with those who took the time to understand FA and show their support through their actions. Those who demonstrated understanding and thoughtful actions around FA safety promoted a sense of connection and trust that their child’s needs were understood and accommodated. These included family, friends, and teachers. Lynn and John described having a close circle of friends they

referred to as allergy-aware friends who were empathetic and understanding of FA. The few friends who fell into this category instilled enough trust and feelings of safety that separate meals did not need to be provided for their son. John provided an example on how they were perceived as trustworthy:

The ones that ask about [FA]. Like, ‘Hey, come over for dinner. Just so you know, we are going to be having blah, blah, blah, and it doesn’t have [FA], I checked. But, we will keep the ingredients so you can take a look. Like, those ones would definitely instill confidence. It was really nice when some would be like, ‘Nope, everything has to be egg-free. It would really bring down anxiety and be more chill. (P07, Interview 2)

For Sarah, mother of a child with multiple allergies, connection was experienced with a close circle of friends who demonstrated understanding of FA, “We have a lot of friends who know about allergies. Two in particular go above and beyond. They are trained with EpiPens® and know exactly what to do” (P13, Interview). She further elaborated:

Both parents are teachers and have been trained on EpiPens before and they are wonderful and smart. And they went above and beyond and taught their eight-year-old through YouTube videos and stuff how to use an EpiPen. And yeah, very respectful. So that’s the reason they are in our safe zone. They took the time and the effort to learn what his allergies were and understand it if they were to be a part of our lives. That is just something they accepted and brought us in. (P13, Interview 1)

Sandra, mother to a child with a peanut allergy (age 10), echoed how friends’ efforts are appreciated and foster a sense of connection and trust.

My close friends are amazing. So, if they were to come over, they bring whole foods – fruit, you know other stuff. And always check, if they were to have a party for their kids,

they will run all the foods by me, like, this is what we are planning to have and send pictures of ingredients and everything. Can [Owen] have this? That part is really amazing. (P09, Interview 1)

Along with Sandra's friends' efforts to understand FA, she also appreciated that her son's friends were supportive of this FA sharing, "His friends are really good. One of his friends, when we went over for a play date, he made his parents put away all of the peanuts and stuff" (P08, Interview 1).

Open, informed communication and actions from people such as schoolteachers and restaurant staff, can foster a sense of trust and connection for those living with a FA. Tom, father of son with multiple allergies, expressed appreciation for those who made effort in FA safety, commenting:

It is helpful when we see the outsiders, they care, like his teacher making sure he is never left out for a birthday or something like that makes a big difference to us. And then, when we went to the restaurant and then the chef coming out and telling us this dish doesn't have any peanuts, it's safe. (P12, Interview 2)

Andy, father of a child with a tree nut allergy (age 8), described how their family and their daughter's school also fostered a sense of trust and safety due to their adherence to FA safety. He shared:

And really, like, from the get-go, our extended family, anybody that has ever taken care of her, her day care, her school has all been completely on board and good with having an EpiPen, avoiding the allergens, not taking unnecessary great chances. Everybody else has been, like, more strict in adherence than we are as a family, which is good and have been inclusive too to make sure that it's not just 'Oh, no, you can't eat this', but more of, 'We

are making a dish without that nut so everybody can have it'. Everything is normal, right?

(P15, Interview 2)

Sarah also described the deep appreciation for those in the community that went above and beyond to ease her concerns about FA safety.

The most stressful, like we talked about, the restaurants, the field trips, the birthday parties, and I will say as an allergy parent, it always feels amazing to have somebody go above and beyond and contact you about what foods are going to be offered, asking what to avoid, making the extra conversations. For example, when we went out for Mother's Day and we had ice cream with the little one and I simply asked the vendor, 'Do you think you could be extra safe and use a clean scooper?' She said, 'My son has a peanut allergy and tree nut allergies, and so we are going to open a brand-new ice cream tub just for you.' And when you find people out there in the world, it just always makes things a little bit better (P13, Interview 1)

Parents also spoke about how siblings were also supportive of FA within the family and at school. Melissa shared that although her other son did not have allergies, he was protective of his brother and always was careful to double check if food items were safe. Sandra also commented that her daughter was quick to speak up for her brother's allergies at school, "my daughter is very good at speaking up for her brother" (P09, Interview 1). Ruby shared that Katie's brother never complained about missing out and always made safety a priority, sharing, "It never bothered him, that as a family we chose not to go to a bakery or something like that because of [sister]. I feel he was more worried about his sister being safe (P02, Interview 1). She also elaborated about how his FA awareness was helpful in his interactions at school.

Oh, he's so supportive. It's never a question, like, he'll often ask 'Can I have this? Is this safe for [sister]? I find he has taken it to the school or classroom and because he has a sibling with an allergy, he's more educated and aware. There has been times he's come home from school and says, 'Oh, so and so has an allergy, and I want to make sure they were safe' or whatever. He definitely has with his education, I feel, he has helped other kids in the classroom at school (P02, Interview 1)

While certain friends, family can foster a sense of trust, others perceived lack of understanding about FA contributed to feelings of stress and uncertainty. Ruby, mother of a youth with a tree nut allergy, captured this contrast by sharing:

There are family and friends who are like family, who I have total faith in and I don't have to worry. And then there is the infrequent visiting of friends or acquaintances that we would say there's an allergy but you would arrive and they would be like 'Ooh, yeah, shoot, okay, let me put this away or let me remove from the platter', and that was stressful and didn't make me feel comfortable. (P02, Interview 1)

Sandra also captured the dichotomy of different types of relationships in her ecomap (See Figure 2, page, 97). Here, she illustrated how close friends and immediate family had a strong connection, while weaker connections with the school principal and other parents at school were a source of stress. Sandra, mother of a child with a peanut allergy, also commented on how a perceived lack of understanding or caring about FA can impact relationships, "I think it strains relationships, when they just don't care and they know right? When they don't know, I understand, but when you know about it?! We just don't see them as much" (P09, Interview 1). She also elaborated on the time and effort on trying to get others to understand the importance of FA safety.

I think it's frustrating. I spend a lot of time trying to foster relationships with people who are, like if my child didn't have an allergy, I wouldn't care to talk to them. You know, it's working through those difficult, challenging relationships and [it's] frustrating when people just don't get it no matter what you do. That's the worst is when they think they get it and they don't, combined with the fact that they don't communicate! And you always have to do it in such a diplomatic way and not let the frustration show about it, like 'Hey guys, just so you know...you know what I found out, it's so boring..' (feigning a happy, friendly voice). (P09, Interview 2)

Children and Youth

Children and youth living with a FA shared their experiences about how certain friends, family, and teacher communication and actions can convey a sense of safety and comfort in managing their FA at school or other environments away from home. Katie (age 14) spoke about feeling safest with those who knew and understood her FA, "...with closer friends it was easier to feel more safe because we knew them better and they understood what was happening" (P01, Interview 1). Darren (age 16) reflected on growing up with a FA placing an emphasis on self and close relationships:

I feel like it's just a part of having an allergy is just growing up and just realizing that you need to rely on yourself and your closest friends and family that you have to actually help you because no one else will. So, just realizing that when you grow up it will really help you with the allergy thing (P18, Interview 2)

Darren felt completely comfortable at his friends' homes, explaining, "I know their parents quite well. I know even their siblings" (P18, Interview 1). He went on to describe how his close friends are always mindful of his FA at school and that over time these friendships fostered a

sense of trust and comfort. He provided an example of his friend bringing snacks for him to school:

I will say it wasn't any actions or words; it was just kind of maturing and just realizing that they will always have my back here for allergies. Like, I know one of my friends just came back from Japan and got a bunch of snacks. And you couldn't really read the labels well because it's in Japanese. But he tried and he, like, tried to translate it for me of anything that could contain peanuts and anything he couldn't translate, he just told me not to eat. (P18 Interview 2)

Jack (age 16) also shared the value of longstanding, close friends understanding his FA, "Everyone in my friend group, they all know about my allergies, so they all know what to avoid" (P21 Interview 1). He further shared, "As long as they are really close to me, like, I have known them for a really long time. Usually, they, ask for allergy information every time we go out" (P21, Interview 2).

For children and youth, visiting a friend's house, where their FA was known and understood was experienced as safe and comfortable. Anna (age 15) discussed how her best friend and her family would take precautions when she would visit.

She was my closest friend, so, whenever we come over to her house, she'd always, her parents would always be extra cautious to make sure she didn't have nuts around in the house when I came or eat nuts in front of me which was really nice. (P04, Interview 2)

Similarly, Katie (age 14) shared her experiences, highlighting the differences in feelings of safety when she perceived that a family understood her FA in contrast to feelings of stress when she believed others did not.

Most of the time I did feel comfortable, same with my best friend's house, her parents were always making sure that I felt safe there and I would always ask 'Hey, is this safe?' and they would be like, 'Oh yeah, oh yeah' and I would always trust them, they would always make sure I felt comfortable. Whereas other people's [houses], at my friend's houses, who I am friends with but not as close with, it was a bit harder. I felt stressful and like, worried about my safety sometimes because their parents were not as connected to my parents or my family as much. (P01, Interview 1)

She further elaborated about building trust over time, not only with her friends, but their parents as well:

If it's just a random play date, the parents might forget or something like that. So, it's hard to build trust if you don't see them that often. You might see them at school, but not the parents. But if you see them a lot, it's a lot easier to gain trust over time. If there are more encounters telling them about your allergy, it is a lot easier to gain trust. And if you are close friends with them, like my best friend's mom, she would always make sure and they really understood (P01, Interview 2)

Having a friend who also had a FA fostered a sense of trust and mutual understanding. Claire (age 8) described having friends with FA as trustworthy due to a shared understanding. She expressed, "Some of my friends ask me what I am allergic to and guess what? Like [two friends] both have allergies. So, that's why I can trust them (P16, Interview 1). She went on to share that "[Friend] always washes her hands and her mouth with when she's done eating, and she makes sure that it doesn't touch me when she didn't wash her hands" (P16, Interview 1).

Children and youth described friends and family who understood their FA; however, they also described experiences when those around them did not. Claire shared that while most of her

friends were understanding of FA, some were not, stating, “Only some of my friends don’t really understand, so they don’t really wash their hands” (P16, Interview 2). Katie (age 14) voiced her frustration with seeing classmates eating nuts at school despite school policy:

They just don’t get it. They will eat it anyway because they are not allergic to it, so they don’t know. So, it’s harder with people who, and some people don’t know you have an allergy or like they just can’t remember, they don’t understand. (P01, Interview 1)

Evolving Acceptance

The second subtheme, Evolving Acceptance, reflects a shift away from social exclusion, teasing, and bullying toward an overall acceptance and normalization of FA within the school and community settings. Incidents of bullying was not reported by children, youth, or parents at school. While families describe the school environment as generally inclusive, there were recounted moments of feeling left out or excluded while at school underscoring that inclusion for students with a FA is still a work in progress.

Parents

From parent perspectives, exclusion, teasing, and bullying at school were not central to their child’s experiences. When asked, parents did not believe their child was bullied because of their FA while at school. When asked about social exclusion at school, some parents did share some experiences of inadvertent feelings of being left out or exclusion during class activities or school events. Nicole, parent of a youth (age 16), shared her son’s experience at school many years ago:

I do remember that students, who at the start, because they didn’t have a policy, that were to sit at a table. And that only lasted a few years and then it was, we had the nut ban that went on and then the kids could sit wherever they wanted to. I think I had mixed feelings,

because of course I wanted him to be safe when they are eating and I am glad he had a safe space to eat his lunch, but also, at the same time, he was segregated from eating lunch with his friends. (P19, Interview 1)

Tom, father of child with multiple allergies, also shared his feelings about his son not being able to partake in eating the same things during social events. “It’s tough because everywhere it’s like, he is left out...or go for ice cream when he can’t have ice cream, he has to wait until we get home” (P12, Interview 1). Another parent also expressed her feelings about seeing her child not able to participate fully in class celebrations with her classmates. Lynn shared, “He never used to be able to have cake or cupcakes, ever. Unless we provided it” (P07, Interview 1). Linda, mother of child with multiple FA, described having her child left out at class birthday parties as she could not partake when food was served. At birthday parties she shared, “everyone gets beautifully decorated cupcakes. And then my kid is sitting at the side by herself, eating something...I can’t even talk about it without getting teary eyed” (P17 Interview 1).

Classroom activities, such as science projects, were also mentioned as times where their children were inadvertently excluded at school. Linda described an incident where the teacher brought in chocolate for a science activity and was unable to participate because of her FA. Linda said “The [teacher] that does two days a week did a science experiment with Hershey Kisses. So, totally excluded my child, like, not safe for her” (P17, Interview 1). Linda said she was bothered when she learned that her daughter was then removed from the classroom and brought out to the hallway to do her work instead. Lynn described another science activity called an egg drop that her son was unable to participate in due to his FA. For another mother, Sarah. She denied that her son was left out at school activities but lamented that her son could not take treats without first checking about safety. She expressed that:

Maybe he feels left out, that he can't just go eat the ice cream sundae from Dairy Queen or whatever, without taking the chance to read through ingredients and making sure Mom checks everything and stuff like that. But, I can't say that he feels left out in any way.

(P17, Interview 1)

Other moments of exclusion at school were described by Lynn and John. For example, they were surprised to learn that when another student brought in eggs into the classroom, he was sent to the hallway by himself to eat his lunch. John shared that segregation because of his FA "... doesn't feel right!" (P07). Although they understood that the intention in that moment was safety, it still resulted in exclusion and segregation of their child from his classmates due solely because of his FA.

Despite the aforementioned examples of parents reporting that their child was left out due to their allergy, there was acknowledgement of an overall climate of allergy acceptance at school. Parents attributed the overall experience of inclusion, and the absence of bullying to a broader cultural shift in which FA is more commonplace, understood, and accepted with the school environment. When asked about whether her son experienced teasing or bullying due to his FA, she responded:

No, they were, their friends have always been really accepting of it, and I think maybe it's just because allergies are more common nowadays than when we were kids. But they would never tease about not being able to eat a certain thing. They'd probably offer an alternative if they had it, but yeah, never, never issues with that. (P19, Interview 1)

Nicole further elaborated on a general sense of understanding and awareness of kids today compared to her generation.

I find that kids are maybe more understanding than a lot of their parents would be. And they'd say 'Oh, [son] has a peanut allergy, and this is what could happen...' because they are educated and those parents come from the same time frame as when you or I do. And you know, they grew up with kids who maybe didn't have allergies. So, I think kids are a lot more aware than parents are. (P19, Interview 1)

Andy, father of child (age 8), shared that from his perspective, having an allergy today feels normal as it is now so commonplace in schools.

Honestly, it feels so normal because there is so many kids with allergies now. So, it is just like second nature to send out invitations to the party and say, 'What are your allergies?' assuming that we are getting back half the kids with an allergy to something. In that sense, it does not feel isolating. (P15, Interview 1)

Martha also reiterated that in general, families within the school environment are more aware of accommodating allergies because they are so common. She explained:

When he was younger and go to the birthday party, we would stay. But now, he's gotten older, and I think too, just because there's so many people being educated on severe allergies now more and more about kids have these allergies. I think a lot of people are more aware, and as Liam has gotten older, sometimes I forget and it is his friends' parents will be like, 'Oh yeah, we have a nut free birthday cake or we have...' They are the ones that are thoughtful to think of someone with a severe allergic reaction, and that reassures us. (P11, Interview 1)

Children and Youth

Children and youth reported no incidences of bullying due to their FA at school, but did share some instances of teasing, unintentional exclusion by teachers, and personal feelings of

being left out. In the school setting, Jack (age 16) said when he was younger he experienced light teasing about being allergic to tree nuts because other students at school thought it meant being allergic to little trees. He shared, “I took it personally when I was younger, but now that I mention it, it was not that bad” (P21, Interview 2). Anna reflected on one experience at her school where a teacher brought in a cake from home and because it was not nut free, she excluded from the class activity and segregated by being put in another room alone. Anna recounted:

One instance I can recall is in elementary school, a teacher brought in a cool, rock-themed cake, like geode-themed with a lot of crystal candies on there that looked really good! But, she said that it might contain nuts and put me in a separate room to prevent me from reacting. So, I just sat there while the other kids ate the cool cake. I think I got Oreos. (P04, Interview 1)

Anna then went on to describe her mother’s reaction when she found out that happened to her.

I think she [Mom] wasn’t very happy about that, at the time I don’t think I really understood the concern very much, but I guess now I can see how, like, seeing your kid just put in a separate room from everyone else, is not a good thing to have happen. (P04, Interview 1).

Claire (age 8) described not being able to fully trust certain teachers at school and gave the following example, “Definitely, Ms. B, but not really Ms. M because she brought in some chocolate into the classroom and popcorn, because of science. I was okay. I just feel like something could have gone wrong if we weren’t lucky” (P16, Interview 1). When asked what happened next, she described being segregated, “I got to sit outside the classroom with a gummy worm” but when asked, denied being bothered by this.

Children and youth shared their feelings of being left out when they were not being able to eat the same foods and share foods with other children during celebrations and social events at school or in the community. Liam (age 10) shared, “I kind of feel left out sometimes or I mean, I just can’t have things” (P10, Interview 1). Claire (age 8) shared her frustration in not being able to have what other students can eat, saying “It’s not fair because other people get to have cool stuff, like, they get to have ice cream and we don’t get to have ice cream” (P16, Interview 1). Cody shared, “I would just like to be like the other kids” (P05, Interview 2). Darren, age 16, reflected feeling different in school because of this food allergy when he was younger:

I just felt, like, I couldn’t, especially since a lot of my friends when I was younger would share food...I always felt like I wanted to, but I just shouldn’t because of the allergy. So, I never got to share food with anybody. I always felt like I was just a little odd in the classroom, (P18, Interview 2)

Katie (age 14) also shared her experiences with FA at school:

Especially back then, when it was a more severe allergy, going to different places was harder, more stressful, and it can suck because you can feel left out of different things. Like, at school, whenever they have treats at school, I could never ever have anything and I would have to be give special treats that the teachers would give, so I could still feel included. (P01, Interview 1)

Owen (age 10) with a severe peanut allergy, shared that during birthday parties, he would be picked up when food was served, saying “Normally, my mom just picks me up while people are eating and stuff” (P08, Interview 1) and playdates outside of the home were infrequent; rather preferring friends coming to his house, a controlled environment.

Although children and youth described feeling moments where they felt different or left out, they generally perceived their relationships and environments were accepting of their FA. For Darren this was a self-realization, reflecting, “For about one to three years it probably did [feel different than classmates]. But then I just realized that other people have allergies, so I am not really that odd and left out” (P18, Interview 2). Katie shared that her teacher always had safe treat for class celebrations indicating:

It was just whenever if we had some kind of food, or the teachers would bring something, or there is a kid’s birthday and they brought things to share with the class, that was always something, just like other little treats that I wasn’t sure was okay or not. It was mostly school or birthday parties that I wasn’t sure about if people brought things. But I would have at school a little treat of my own that I would have so I would feel included.
(P01, Interview 1)

Jack expressed, “Yeah, they [kids at school] are really respectful now, especially at my age” (P21, Interview 1). Katie also echoed this sentiment and elaborated by sharing, “Nobody would ever tease me, and I always felt comfortable with it. I was never teased about it or self-conscious. It was always normal to me and okay” (P01, Interview 1). For Sally (age 8), she never felt left out and was able to fully participate in school because it was nut-free, “We are not allowed nuts at school and that makes me feel safe” (P14, Interview 1). Finally, Anna reflected on her school experiences over the years and shared, “I feel like it is better than it was, like, 10 years ago. People are, kids are more understanding and aware of what allergies are” (P04, Interview 1).

Setting the Tone at School

The subtheme, Setting the Tone at School, refers to the importance of school leadership and teachers working together to create a safe and inclusive environment for students with a

Central to this subtheme, is making a commitment to safety through clear communication, ongoing education and awareness, and adhering to FA policy and practices. This commitment to safety provides reassurance to parents about allergen safe practices and for students with a FA, it fosters a sense of inclusion and normalcy. Conversely, school leadership that does not have clear and consistent messaging about FA policy within the school community can create feelings of anxiety, uncertainty, and frustration about the commitment to FA safety.

Parents

Open and clear communication between teacher and parent of a child with a FA was paramount to perceptions of a commitment to safety in their child's classroom. Lynn stated that, "I think there is quite a sensitivity of teachers to make sure the tone is inclusive" (P06, Interview 1). Linda, however, expressed variability in her experience with teachers understanding and management of FA in the classroom.

So, I have had in the school, I have had wonderful teachers and I have had teachers, that I don't know, if they are as concerned... There have been many days that he has come home with a new candy as a treat that he was given as a prize for something with no ingredients on it and has to trade them and say 'sorry, you can't eat that, but here is something safe' So, that was kind of not wonderful. I have had conversations in the past with teachers about the allergies and obviously it did not seem like it was a priority, or they don't know the severity, right? If you don't live in the allergy world, maybe you don't understand it. But the teacher he has right now is wonderful. She contacts me for every food activity, sends all of the ingredient lists on pictures asking if this is safe or if I wanted to send my own safe items. This year has been wonderful. So, it has been a varied experience. I have had teachers in the past, the kindergarten teacher in particular, I asked

if there was a protocol? Do children sit at a different table for lunch, are they washing their hands before and after they eat? And it was just brushed off, like, ‘Oh, we can’t control what they bring in, you just have to make sure that your child is washing their hands. (P13, Interview 1)

Sandra shared when she noticed that teachers prioritized FA safety, she would make sure to recognize this, stating, “we gift card a lot, especially if someone goes out of their way to make my child safe” (P09, Interview 1). Another parent of a youth with FA, reflected on the differences between the early school years versus high school. From her standpoint, “I would say the teachers were on top of it more so in early years than they are now. Her homeroom teachers were always good; however, there were still mishaps” (P02, Interview 1). She further elaborated,

Once she got to elementary school, I felt confident there. They treated allergies very seriously and they had posters on the door...So, it was in your face every single day, for the kids, for the parents picking up their children, and for teachers and substitute teachers. Younger grades, I feel like the teachers are all over it. The kids are aware. Maybe the parents are told more or more aware with it (P02, Interview 1)

Conversely, she expressed a lack of confidence that her high school teachers are even made aware of her daughter’s FA,

She doesn’t wear an EpiPen belt anymore nor does she wear a medical alert bracelet like she used to and that was by her choice. So, there is no other way she is identified as having an allergy. So, definitely, as she ages up, there is less and less information to the teachers on who has an allergy. And, in the great hall where they have hot lunch, there is no signage, no listing of names of kids with allergies (P02, Interview 1)

Parents described taking a proactive approach at the beginning of the school year by speaking with teachers to ensure awareness of their child's FA and to understand how FA would be handled in the classroom. Nicole reflected that she always connected with the teacher, "I would reach out to the teacher within the first, you know, week of starting school and just explain the situation usually" (P19, Interview 1), elaborating:

They always get the file transferred over from year to year, and there's a big paper that says that they have allergies, but, I always like, to touch base too and just say 'If you're ever having a special celebration and you know you need me to send a cupcake or you need me to send candy, just let me know. But, a lot of the teachers were actually very accommodating, and the fact that they would just supply candy, that was peanut free also (P19, Interview 1).

Teachers who set the right tone with students and their parents at the beginning of the school year was perceived to impactful in fostering a sense of comfort and security about the year ahead. Linda reflected this by sharing that her teacher gave a presentation about FA to her classroom to raise awareness, "They did a whole presentation on food allergies in kindergarten around Halloween time" (P17, Interview 1). Sandra described her son's teacher' timely effective communications to the classroom:

Yeah, we have been fortunate enough to have her two years in a row. Last year, my husband and I caught her off guard, by surprise the first week of school. We ambushed her and told her about it. And then last year, right off the bat, she sent an email to parents to introduce herself, that her name was Miss W and the assistant teacher in the classroom, and then the second paragraph is 'We have a severe peanut and tree nut allergy in the classroom. Do NOT bring anything in. And then what she did last year and this year, she

got [son] to give a little speech on this, which I think really bring ownership for [son] and also makes kids, I think it creates buy-in at this age, you know, they can put a face on it.

(P09, Interview 1)

Parents described ongoing communication with teachers throughout the year, particularly about food coming into the classroom for celebrations or activities, which was deeply appreciated. Sandra expressed, “His teacher is amazing. She would email me and say we are going to have hot chocolate can [son] have this?” (P09, Interview 1). Nicole also recounted:

The teachers would always, if they were having let’s say a special pancake day, they would email me a picture of the label or saying that they brought certain cupcakes from such and such as a store, would that be safe? (P19, Interview 1).

Parents acknowledge that while strong communication with their child’s teacher was desired, there was also an acknowledgement that this was additional workload for teachers. Linda stressed, “It’s a lot of work for the teachers. She takes her own personal time to reach out to me and in the afternoons and outside of school hours and it’s her personal time that she is using” (P17, Interview 2). Linda further reflected on the commitment of the teachers at her daughter’s school:

So, every single teacher knows [daughter] and knows her allergies. The music teacher, she’s in choir, and the music teacher called me on my cell phone after hours and said ‘How can I make this a safe space for [daughter]? What can I have? And then I said, ‘I’ll bring snacks so everyone can have’. And she’s, like, ‘No, just tell me what it is and I’ll go buy it’. Like, you know, that the kind of support that, I don’t want to say I expect, but I, but, like, that’s what makes me happy and comfortable as a mom to send my kids to school. (P17, Interview 1)

Another parent made the distinction between teacher communication and school wide communication in her son's school, noting, "I think from the classroom teachers, yes, overall, as a school, there probably wasn't as much "(P19, Interview 1).

While teachers are often the primary point of contact for parents and students in the day-to day classroom management, some parents emphasized that the responsibility ultimately lies with the principal for setting the tone for how FA policies are communicated and implemented school-wide. When leadership was viewed as strongly committed to FA safety and inclusion, parents described a supportive school climate. In these contexts, FA policies were not only communicated effectively, but were also modeled and reinforced in the classroom, fostering a shared understanding. In Sandra's words:

I think that schools have such a big impact on how kids treat other kids with food allergies, especially in elementary school. It sets the tone of how these kids grow up. And [son's] teacher, teaches inclusiveness and kindness and I think that really translates into why he hasn't had experiences, like a lot of kids' experience. (P09, Interview 1)

Parents described their communication with their child's principal and shared how these interactions shaped their perceptions of safety.

So, my first conversation was with the principal of the school. We obviously had to come in, there was a form to fill out, stating what allergies he had. You need to provide the school with two EpiPens. When I sat down with the principal, he seemed very confident and I didn't question anything, it was a nut free school. In the past, there had been other foods added to our list, like fish. That was a school wide allergen at one point, but it is no longer there so that child must have left the school. So, I knew that there were other allergies. I knew they had lists in order. I knew they had a protocol about where the

EpiPens were. I knew that all the teachers were trained that were going to be in contact with the children with allergies, with EpiPens. I felt quite confident; however, (chuckles), it's not as confident now that I am in the school. (P13, Interview 1)

Linda recalled the conversations she had with her daughter's principal regarding the school's approach to FA management was a key reason she chose that school for her daughter, explaining:

It's the reason why I picked this school. They provided her with an EA [Education Assistant] for kindergarten and grade 1 during snack and mealtime. In second grade, lunch fully funded. So, just like, over the top supportive. They're very strict about the nut policy. I, the PSG, the parent support group, we'd order lunches and we're like, we can't go here because they are going to put nuts in this dish and, like, yeah, the teachers can't have nuts at school either. (P17, Interview 1)

Supportive principals also demonstrated a climate of FA safety through school-wide communication. When asked about communication coming from the school, Martha indicated:

It's on the newsletter they send it out every month. At the very bottom of the newsletter, they have that it is a peanut aware or allergy aware school. They are even with the sensory, about scents, they have posters up on the wall about that too. (P11, Interview 2)

Andy also reflected on how the school's communication about FA contributed to his sense of reassurance and described why he felt his daughter was safe at school:

Well, it's like, a nut free school and it seems to be followed routinely. I don't want to use the word strictly enforced, but it is definitely at the forefront of conversations, events, activities, everything. They are always reminding us that it is nut free. And I have never been there to see when nuts are brought into the building to see what a containment

situation looks like, but, overall, they just give us confidence that it's a nut free facility.

So, we don't really have to worry about exposure in the school, just because it's on everybody's mind at school. (P15, Interview 2)

Sandra emphasized how a particular principal made a significant impact on her family's sense of feeling supported and safe at school. For Sandra and her family, the principal's ability to confidently articulate FA safety practices and demonstrated empathy directly influence their decision to enroll their children at this school. She reflected on this style of communication:

I think he just really empathized; he listened. He kept saying 'I understand how stressful it must be for you to entrust your care of your son to us', and he said 'Listen, we have seven staff members who are trained on first aid and how to use an EpiPen. We have staff members who have food allergies that know how to use an EpiPen. I, myself, know how to do it.' And then he said, 'This is what we are going to do' and as a result of that meeting, the first initial meeting with him, we were just so wowed over. This school isn't even the closest school, but it was our closest French Immersion catchment school, and we just decided to just drive there. It is a good 10–15-minute drive and he was just so amazing, and I find out from a lot of other parents in the district that he was just an overall amazing principal. And as I started, when my son started school, you know, relationships are reciprocal, right? Like, if your principal is really good to your kid, you do what ever you can to support them. I fundraise for them, organized a lot of events, involved with PAC, so I got to know him better. And then I think that they, it was just easier to get his ear, to make sure my son was kept safe, right? (P09, Interview 1)

In contrast, when principals were perceived as less engaged or inconsistent in their commitment to FA safety, parents described greater variability in how policies were applied and

communicated across the school. Sandra described her son's current principal's approach to implementing FA policy in the school stating, "They are a nut-aware district. And the current principal approach to it is that they will only do it by classroom basically. He won't apply it across the school as previous principals have" (P08, Interview 1). When learning about a new principal in the school, Sandra shared her experience of attempting to establish a connection, stating:

For this school year, September, I decided to be proactive. I sent him an email well before school started and no response, I sent another email, like, it was just email after email, and then finally, like, called him and no response. And I got the school's secretary involved to talk to him. And it wasn't until the Terry Fox Run, which is like, end of September where I decided I would walk into the office and I know he will be at school and just sat outside his office and just waited for him. And to which he apologized, he was like, 'Oh, it's been really busy. See, I have a stick note for you, blah, blah, blah'. And then he was asking about it and he was like 'My son has what and we were kind of wondering about his food allergies' and I said, 'Oh yeah, it's really interesting managing it and I hope you don't have to go through that' And then as we were parting the meeting and he said, 'Oh, by the way, does your husband's side have food allergies?' and I said, 'Yeah' and he goes 'Now I know who to blame.' And it was totally inappropriate coming from a principal. (P09. Interview 1)

For parents of children with FA other than nuts, nut-free or nut-aware school policies were described as largely unhelpful and voiced frustration. John highlighted this in sharing:

You would get a bit of material from the school saying, you know, we are a nut safe school and there was a bit of 'Come on guys, like, there is more allergies than just nuts.

And our child has an egg allergy. And I don't like to be self-righteous or in the face of the system, but it was a bit of, 'Guys, you have a child in your care in the school system that has an egg allergy, can you at least send emails also advising that there is an egg allergy or other allergies?' (P07, Interview 1)

He expressed his frustration, stating, "It kind of bothered me that the school system wouldn't communicate this, because they had a child in their care that was allergic" (P07, Interview 1), adding, "for us, it did not hit on our parental need". Lynn, John's wife, went on to say that they advocated for emails to be sent to parents in their son's classroom so that other parents were aware of another type of allergy in the classroom.

Children and Youth

Children and youth did not elaborate extensively on the role that teachers and their principal played to help them feel safe at school. When asked what her teacher did to make her feel safe, Sally (age 8) replied, "Not much because the school doesn't allow nuts. But they check everybody's food to see, they look at everyone's food to make sure" (P14, Interview 1). Claire, (age 8) also succinctly responded by stating, "My teacher will let everyone in the class know" (P14, Interview 2). Owen (age 10) shared his reasons for feeling safe at school, "A couple of students, including me and a couple of teachers have nut allergies, so basically throughout the school, you are not allowed to bring it" and as because of this, "I feel very safe with my friends and my teachers and my classmates" (P08, Interview 1).

Children and youth participants indicated that teachers had safe treats on hand for them for class celebrations. These treats were either purchased by the teachers or brought in by the parents in advance. Katie commented that her teachers tried to make her feel included at school by offering her safe treats, "teachers would always make sure and be like 'Hey, do you want one

of your little treats’ or ‘are you able to eat this?’ or make sure I knew that I was okay to eat it or what not” (P01, Interview 1). Liam also shared that teachers during class celebrations, would offer a safe treat, “They will just give me something that is peanut-free” (P10, Interview 1).

Darren’s teachers would always let him choose a safe treat first.

Some children and youth participants described what actions were taken if nuts were brought into the school. Katie described a teacher’s response when she told them about students eating nuts in the classroom:

They made sure to talk to the person directly and say, ‘Hey, you can’t have nuts, please be aware of that.’ I think it should be addressed though more often to every person, because lots of people don’t know, so they kind of like, don’t care and they don’t understand that these people with these allergies, it’s unsafe for them and dangerous, so maybe having told it to everyone [in the class] would have been more effective (P01 Interview 1, lines 123-129).

With respect to principals and FA safety practice, different approaches taken by principals appeared to evoke different safety climates in schools. Darren (16) reflected upon a breakdown of adherence of nut-allergy policies in his elementary school he experienced, recounting, “I feel like for the first, like, two years, it was really well-enforced, but then, it went really wrong for us. Because then we had a new principal and it kind of just fell apart” (P18, Interview 1). Owen (10) described how his old principal was supportive of his FA and would communicate this to the school community at the beginning of the school year. Owen recounted,

He sent an email out to the whole school, at the beginning of the school year, telling people to not bring it and I think if kids did have it, then they would eat it in his office or something like that, I think that was the set up. (P08, Interview 2)

When asked what would make him feel most comfortable and safe at his school now, he answered simply, “I would like to have my principal from the other school back because he was really good with my allergy” (P08, Interview 2).

Some youth noted the differences between junior school approaches to FA to their current middle or high school environments. Katie (age 14) reflected on the difference between her current high school experience and her junior school experience with respect to nuts at school and described a different approach.

Now, I feel like there is more nuts at school. I remember when I was younger though, they [teachers] made sure there were no nuts. There was this one kid who brought in a peanut butter sandwich, and they made sure, they were like, ‘Get rid of it’. They wiped down the table and made sure everything was cleaned up and safe because there were other kids in my grade with peanut allergies. So, when I was in the younger grades, it was more told upon and dealt with, whereas now, it’s not really dealt with in the older grades. (P01, Interview 1)

Anna (age 15) also noted how approaches to FA shifted between junior and high school, and as well, commented on how different schools enacted similar school policies.

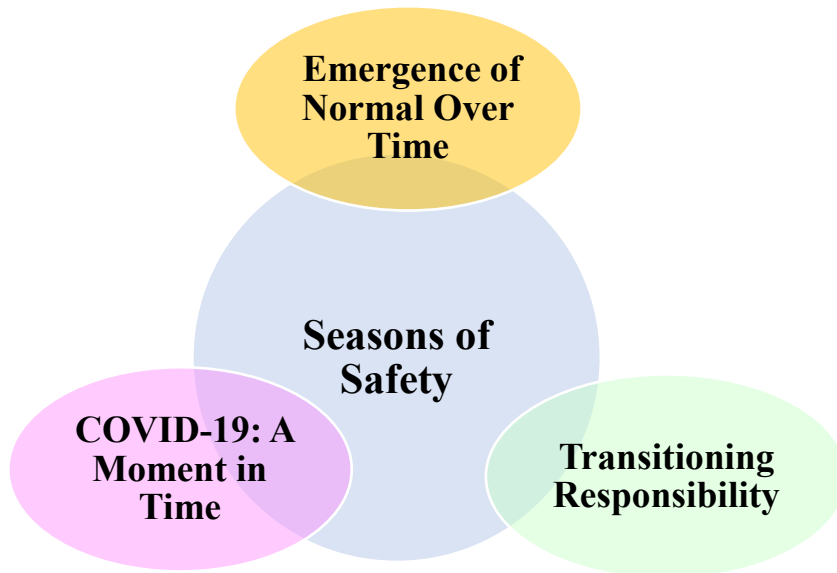
In the school I went to until Grade 2-7, the school seemed very serious about FA safety. Ms. H [school administration] made sure that my parents filled out health forms about FA and that my EpiPens were not expired. Their cafeteria did not serve nuts or seafood either for hot lunch. We weren’t allowed outside food to be brought in for class celebrations; everything had to be ordered through the cafeteria. They had FA signs all around the school even in the high school section. If a teacher noticed that someone brought in nuts in a snack, it was dealt with immediately. Oh, and the newsletters would always have

reminders. My current school is also nut-aware and goes from junior kindergarten to grade 12. My mom still has to fill out a form, and I have to have an extra EpiPen at the front desk. But I kind of feel like their policy is not as enforced other than no nuts at hot lunch and the occasional reminder in the newsletters. I don't think the principal is too involved with that suff. There is no signage that I have seen in the school. Outside food is brought in by teachers and high school students who order from Skip the Dishes or something like that. Just last week, they sold snacks at lunch that were from places that I know has nuts. I can't talk about how strict the junior school is here, but in high school, it is sort of left up to me to decide what's safe. (P04, Interview 2)

Despite both schools having nut-aware policies and spanning all grade levels, Anna's reflection highlights key distinctions including visible signage throughout the school, differences in allowing outside food in the classroom, and her overall perception within each environment.

Lived Time: Seasons of Safety

Lived time, according to van Manen's existential framework, reflects the subjective experience of time and is an essential part of how we exist, experience, and understand life circumstances (2014). The theme for lived time, *Seasons of Safety*, theme reflects the evolving, temporal experience of living with FA marked by shifting perceptions of risk, adaptation, and responsibilities over time and developmental stages. This theme is supported by three subthemes: *Emergence of Normal Over Time*, *Transitioning Responsibility*, and *COVID-19: A Moment in Time*, each of which are explored below. See Figure 7 for a visual summary of the lived time.

Figure 7*Lived Time***Emergence of Normal Over Time**

The subtheme, Emergence of Normal Over Time, captures the transition from early diagnosis and learning about how to manage FA safety to a growing sense of familiarity and routine as children and youth, along with their parents gain experience, knowledge, and confidence over time. Through lived time, FA safety becomes increasingly routine, manageable and an expected part of living with a FA. Although many participants described an emergence of normal over time, this did not necessarily signify the absence of stress or anxiety, particularly for families managing severe or multiple FAs.

Parents

Parents reflected their experiences when their child was first diagnosed with a FA, characterized by heightened anxiety, worry, and hypervigilance. Nicole shared, “I think in the

beginning it was a lot harder, but I think it just became a norm for us” (P19, Interview 1). John and Lynn began by sharing, “We are a lot more chill now, just because it [FA] has improved a lot” (P06 Interview 1); whereas around the time of initial diagnosis and initial years following, John shared:

We’d have EpiPens and we read the label on everything, and we were just like ‘AHH’ [overwhelmed], so hypercautious about everything. Like, there were zero eggs in the house. We were in full freak out mode. And restaurants of course, total avoidance. Like, we wouldn’t cook eggs in the house, we just didn’t have it in the house. You know, you don’t want to expose your child to this. For a long time, he didn’t eat anything in restaurants too. We always brought our food until he was about five or six. Then we started exploring more. (P07, Interview 1)

Lynn contributed her perspective also reiterating that their family has loosened up restrictions through living through food challenges. When asked about living with a FA the first few years, she shared:

So, initially we just, like, practiced complete avoidance. We read every single label with a fine-tooth comb, right? We often provided our own food when he went on playdates, or with my parents, or if he had to be babysat. When he was babysat, we left really clear instructions on what he is allowed to have and put a lot of options. And we were really strict about, like, you can’t have this, or you can have this. [You] spend a lot of time advocating and educating. And we didn’t take a lot of risks. You don’t have to take risks, so there are always other options even if it’s boring and bland. So, that’s how we operated for a long time. (P06, Interview 2)

Parents also expressed how initial feelings of stress gave way to a sense of routine and normalcy. For Nicole, mother of two with FA, the initial shock of adapting to FA caused the family stress, expressing, “So, in the beginning, I think it was super stressful. When I was growing up, a peanut allergy was fairly rare. I probably knew one person who ever had it. So, in the beginning, I think it was more panic and how are we going to get through this? And how do people live life with allergies? (P19, Interview 1). She also described her fears of having others care for her children, “Those first few years were tough and feelings of letting them go to a babysitter or a birthday party or grandparents’ house and that not everybody understands to the same level as you did” (P19, Interview 2). She then described that over time, FA management became a normal part of life, “It just became a norm for us because it wasn’t just one it was two of them. And, so, it was very normalized that we just couldn’t have that, but we could always find an alternative” (P19 Interview 1). Andy also shared that as a family, “where we are now, we are a lot less worried then when she was initially diagnosed” (P15, Interview 1). He then elaborated on he and his wife’s initial response and reducing the stress through education.

It’s kind of like, complete avoidance [all nuts] and I feel like the EpiPen was a lot scarier prior to us finding out about and going to the course at [hospital]. Like, it used to be that it’s like ‘OH MY GOD, AN EPIPEN!’ But I think we would [now] both feel confident in administering an EpiPen and following the procedure if she has an anaphylactic [reaction], obviously we don’t want to go there. (P15, Interview 1)

Managing FA over time became less stressful for many parents in part by their children maturing and taking on more responsibility. Tom shared, “He’s older now, so he has a lot more responsibility. He is more self-reliant. And so, I think it is getting better now that he is older” (P12, Interview 2). When asked levels of stress they experience when their son is at school,

Lynn stated, “It’s less no because he is his own advocate” (P06, Interview 2). Melissa, mother of a youth with multiple FA, also highlighted this by sharing:

When he is little, I worry because he doesn’t know which one, right? Which one is good, which one is bad for him before. But now, you know, we know that he can manage to be alone in a restaurant because he is very, you know, he reads all the labels anyways. He asks now, he knows how to ask now, he knows how to read. So, when he is younger, yeah, it’s more scary. (P20, Interview 2)

Parents describe arriving at an acceptance of FA, adjusting family practices for safety, and normalizing it within the family. Linda shared, “So, we sort of accepted [FA], and we just adapt our lifestyle” (P17, Interview 1), and stated that, “we make her life as normal as possible”. Ruby articulated that within the family there is now “never any concern because it’s under our roof and we feel quite comfortable” (P02, Interview 1). Nicole further expressed her thoughts about her children’s response to living with a FA, “Our kids have always been really understanding of the whole idea [FA]. They have never really had a cry or said, ‘Why me?’ and ‘Why does this have to happen?’ We’ve really tried to normalize it” (P19, Interview 2). Sandra reinforced to her son that if there was ever a food type of food that he could not eat, an alternative would be sought. “I tell him that if there is any food you want to eat, I will find you a safe version or I will make you a safe version” (P09, Interview 1). She went on to say that she always tries instilling the following message, “The allergy is out of his control and does not define him. We are defined by our actions, our words, by what we do, our controllables, and these are within our control.”

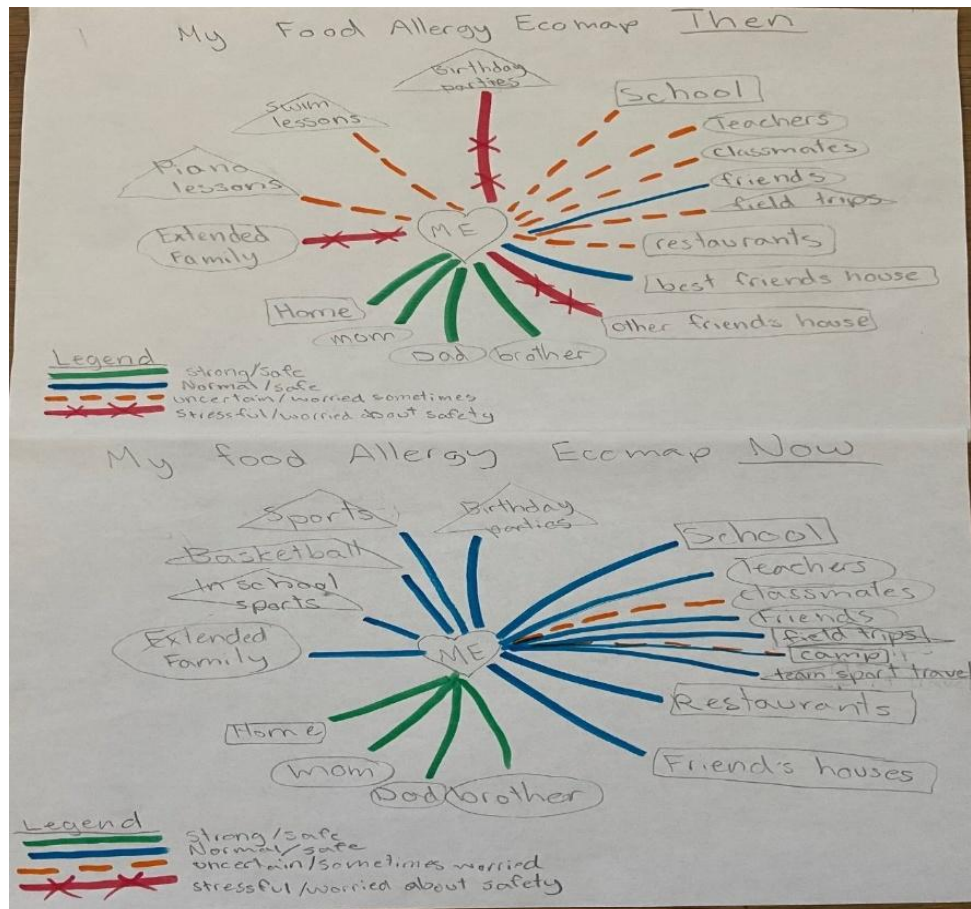
Children and Youth

Children and youth living with a FA often characterized their present experiences as a normal part of their everyday lives. Youth participants reflected on years past and noted that

feelings of worry about safety were more pronounced when they were younger and these feelings shifted as they matured and gained experience and confidence. For example, Katie (age 14) depicted this shift through her two ecomaps entitled *Then* and *Now* (See Figure 8 below).

Figure 8

P01 Youth Ecomaps-Then and Now



These two ecomaps illustrate how Katie's experience with FA changed over time. In the first ecomap, strong and safe was limited to immediate family within the home and normal and safe for her best friend's house. The school environment, including teachers and classmates, was depicted as uncertain and worried as it pertained to FA. Even more stressful and worried was in environments and relationships with extended family and going into other's homes. At present, the school environment and all relationships, with the apart from classmates were depicted as

normal and safe. She explained her being comfortable now as “just feeling relaxed and not worried about my allergy, and also forgetting about it, taking it as something that can’t go away anymore and is just a part of me” (P01, Interview 1). She shared:

I feel a lot safer now, um, because I know how to go about my allergy more and now that it’s, like, less strong of an allergy, I can feel more comfortable, like, eating different things and like, knowing what to do if something does happen. (P01 Interview 1)

Katie elaborated on how FA has become normalized.

It’s pretty normal now and I barely think about it, just part of me now. It doesn’t make me think about it that much, it’s just normal. Before, I would usually think about it, and think about the scenarios that might happened, like going to friend’s houses and being really scared and not knowing what I could eat. That would go through my mind a lot, but now, it’s just part of me, and I don’t think about it that much. (P01, Interview 2)

Darren (age 16) explained that although his allergy was a significant concern when he was younger that now have receded with maturity. He shared:

Although I mostly feel quite safe with honestly all my allergies or just peanuts the only one I really have. I feel as a kid, I was a lot more concerned about all of this stuff, but its kind of only a select few things that I actually feel I need to be cautious about now. Like, things at school and like a friend’s house, I can trust him enough to know that I can’t eat peanuts. (P18, Interview 1)

Jack (age 16) also normalized FA safety as always being part of his life, thereby expressing that “I don’t think it [FA] really had a big impact. We have been careful my entire life so that [an allergic reaction] doesn’t ever happen” (P21, Interview 1). He also shared that, “It’s just because I have been dealing with this my whole life, since the thing [anaphylaxis] that happened. It

happened when I was really young, so it's kind of normal for me to avoid stuff now" (P21, Interview 1). Cody (age 12) whose severity of egg allergy has diminished over time and how this has improved his sense of normalcy, succinctly stating, "Well, like, it's a lot better now. Like, previously, it's been different, but now it's normal" (P05, Interview 1). Children and youth expressed moments when they felt normal and safe throughout their interviews. These feelings were described within the contexts of lived space (e.g., home safe home) and lived relations (e.g., value in those who get it).

Transitioning Responsibility

The subtheme, Transitioning Responsibility, refers to the gradual shift of FA management from parental control to greater independence and self-management by children and youth. This transition was described as an ongoing process embodied through role modeling and a gradual transfer of knowledge about FA management to prepare their child for independence as they matured. Parents shared their experiences about continually educating their child about safe practices and progressively handing over more responsibility as appropriate. Children and youth also expressed these experiences describing how over time and practice they assumed more responsibility and advocated for their safety with increasing independence.

Parents

Parents described an ongoing effort to educate their child about safe FA practices to ensure their safety in their absence and as well, to equip them with the skills necessary to become fully independent. Parents described teaching about FA and allergen avoidance starting at an early age. Lynn recommended, "I think families with food allergies spend a lot of time educating their child. Mistakes still happen, especially when they are young. So, the best practice is complete avoidance when they are younger, until they can advocate more clearly for themselves"

(P06, Interview 2). Nicole talked about the focus of FA education and safety remarking, “we just really, really drilled it into them when they were little” (P19, Interview 1). She elaborated further:

When they were really little, they probably didn’t understand what an allergy meant and why they couldn’t eat it. So, just trying to explain it to them in ways that ‘We don’t know who it would affect you. You could get hives, or you could throw up or worst-case scenario is that your throat might close and you would have trouble breathing and then that could be very serious’. And when things came up in the media and stuff, I remember there was a story of a young adult, I think he was in high school or college, and his friend had given him some sort of chocolate chip cookie and the boy had ate it, just thinking, like, it’s a regular chocolate chip cookie and then he went into anaphylactic shock after that and I believe he passed away. And I just remember the boys were old enough, just sharing that these types of things can happen and that’s why we have to take things so seriously. And I think, you know, right from that moment, they did and they understood that and there could be really potential hazards if we do this. (P19, Interview 1)

As children grow and mature, parents described a shift between parental guidance giving way to growing independence. Even as children continue to depend on their parents for FA safety, they also start to demonstrate their own FA safe practices and emerging autonomy. Andy illustrated this parent-child transition by giving the following example:

She would rely on us for all the food in our house. But she will check labels and confirm, say, like, when we are ordering ice cream, ‘Does this one have?’ or ‘That’s got pistachio in it. I am not going to order anything from there.’ Like, she’ll manage that for her

allergies. When it comes to, like, choosing an ice cream from a cooler, then she will come to us for confirmation on what's a safe pick for her. (P15, Interview 1)

Andy also described his messaging to his daughter and noting her increasing independence stating:

As she gets older and she starts making her own food choices and going out on her own, it's to continue carrying her EpiPen, like she does, just in case of emergency and to read labels, and to be aware of what she is eating and to make sure she avoids cashews and pistachios as she is doing now. So yeah, I can't criticize her much at all. She does a good job. So, basically 'Keep up the good work!' (P15, Interview 2)

Another parent, Martha, reflected on having increased peace of mind knowing her son can advocate for himself, sharing, "Because he is older now, I have more faith and trust in his ability to say 'No. I am okay. I am good. I am not going to try that'. It brings me comfort as he gets older; he and more aware" (P11, Interview 1).

Parents also expressed the importance of having their child learn autonomy in managing their FA. Ruby, mother of a 14-year-old youth, described teaching her daughter to have agency over her FA early on. She shared:

We always taught her from a young age that she needs to be in charge of this, so, at restaurants, we weren't going 'Our daughter has a tree nut allergy...' Ever since she was able to speak it and understand it, she was at the restaurant telling the server that she had an allergy and to what exactly. (P02, Interview 1)

Ruby went on to share that their family made a concerted effort to demonstrate that FA can be managed. She said, "Definitely, educating her and empowering her and confidently amongst us parents, showing her that we can figure this out, we can get through it" (P02, Interview 2). As

her daughter matured, she recognized that her parental control would lessen, thus highlighting the importance of teaching her early on to be independent with FA management.

So again, it's losing that control as she grows up, but she's also confident on her own to always have her EpiPen around, with her if she wants to leave the house and that she knows how to use it if need be. So, it has definitely changed as she ages, probably more so for her, but I'm still, I would say maybe more heightened that she actually still has an allergy as she is becoming more relaxed about it. (P02, Interview 1).

Nicole described finding the balance of teaching independence and promoting inclusiveness. She expressed her family approach to teaching FA safe practices:

You always wanted them to feel like they fit in and that they were safe. So, just having the right balance of education and safety and awareness, just made it easier for them to live their lives on their own and become independent. We had a trainer EpiPen, we had both the Allerject and the EpiPen version, so we showed them all how it worked and practiced on the little trainers. (P19, Interview 2)

She also reflected that her sons, both with peanut allergies, took on more responsibility as they matured, "They got really good at taking over for us, just asking the questions. And sometimes they were even more diligent than we would be especially as they got older" (P19, Interview 1).

Child and Youth

Youth participants, and to a lesser extent children, described a gradual increase in responsibility for managing their FA over time. Overall, younger children relied on their parents and trusted adults (e.g., teachers) to avoid their food allergen and keep them safe within their environment. Children and youth describe letting others know about their food allergy, remembering their EpiPens, not sharing food at school, and learning to read food labels. A few

examples are explored below; however, noting transitioning responsibility is also highlighted in the lived body, caution cultivating character sub-theme.

Parents taught their children about FA management and safe practices early on. Jack (age 16) shared, “My parents always taught me to be careful” (P21, Interview 1). Katie (age 14) described her parents’ role in her FA management, highlighting “they are always supportive of making sure I know what I need to eat, make sure I feel comfortable if I am going somewhere I am not sure about, like, camps. They make sure to tell me to ‘just let people know you have an allergy, make sure you have your EpiPen, if you need it tell the teachers and just make me feel comfortable for wherever I am going” (P01, Interview 1). Over time, with maturity, education, and experience children and youth took ownership of their FA. Anna also reflected on the transition towards independence and stated:

When I was younger, I didn’t really know what it [allergy] meant and just listened to my parents when they told me I couldn’t have them [food with nuts]” Moreso when I was younger, my parents were, a bit more restrictive in terms of what I ate. But now that I am in high school, I get to choose a bit more of what I can eat. (P04, Interview 1)

Children and youth described gaining confidence advocating for themselves by speaking up for themselves at school or other environments. Even as young as eight-years of age, Claire shared, “I need to remember to remind people that I have food allergies because otherwise they will not know and then may be get me sick” (P16, Interview 2). Jack (age 16) shared his comfort in self-advocacy. He mentioned, “Yeah. I’d be comfortable asking if there is any nuts or fish in it [food]. And if I am not really familiar with the food, like, if it’s the first time I have seen it, then I’d probably just decline it” (P20 Interview 2). Katie (age 14) described always feeling

comfortable letting others know about her food allergy. “I’d always tell them I have a tree nut allergy and make sure they knew that” (P01 Interview 1, lines 144-145).

Children and youth described their increased confidence and comfort in reading food labels. Anna shared her experiences about understanding food labels:

When I was a lot younger, the only label I really knew was if the package had a big symbol that said ‘does not contain nuts’, then I would be like, ‘Okay, I can have that. But, as I grew older, I learned to read the backs of the packages for the labels and what they contain. (P04, Interview 1)

Jack (age 16) expressed his independence and confidence in reading labels, noting, “I just read every label. If I buy food from a market, I would always read the labels before eating it” (P21, Interview 1). Katie (age 14) expressed how helpful it was for her to learn how to read food labels, “That was really helpful, knowing how to read it myself, so I personally knew it was okay because sometimes people didn’t know how to check labels either. Like, I didn’t know how to check labels until I got taught, so me checking them really helped me feel more comfortable (P01, Interview 1).

Feeling a sense of preparedness about using an EAI was also part of the transitioning responsibility of FA management from parent to child. When asked if he would be comfortable giving himself an EAI, Jack (age 16) responded, “Yeah. I am pretty sure I have been doing it, the practice ones, every single time I went to the clinic. So, I am pretty sure I am really confident with it” (P21, Interview 2). Katie (age 14) also shared that she was taught how to use an EpiPen but noted that in the moment it would be a scary event.

I was always taught how to use it, like, with practice ones. I made sure I knew how to use it. ‘Blue to the sky, orange to the thigh’. But I feel like in the moment, I would have to

probably freak out a little. Like, my mom would teach some of my friends when the came over how to use it. But yeah, I think it's good when I learned how to use it (P01, Interview 2)

COVID-19: A Moment in Time

The subtheme, COVID-19: A Moment in Time, reflects the felt impact during the pandemic on the daily lives of children and youth with a FA, and their parents. Although public health measures implemented in schools such as eating with class cohorts and increased sanitization protocols, families described minimal impact on their lived experience of FA.

Parents

Parents did not place emphasis on the COVID-19 pandemic as a period of time that impacted their lived experiences significantly as it related to their FA at school. When probed, parents acknowledged that public health measures enacted in schools such as increased handwashing, sanitization of tables and eating in smaller class cohorts were all helpful in allergy avoidance by minimizing the cross-contamination as a mode of allergen exposure. When asked, there was acknowledgement that the increased sanitization was helpful in reducing cross-contamination in the schools. John shared, “He wasn’t exposed to anything before it, so the precautions were good about washing hands and wiping down surfaces, but...I am sure all the sanitizing efforts helped” (P12, Interview 2). Nicole noted that the increased sanitization at school has persisted after the pandemic:

When they went back to school they were sanitizing more, and I think still do to this day. They are a lot more diligent washing or sanitizing before they eat whenever we’re out or whenever they’re at school, but I don’t think it changed too much for them allergy wise. (P19, Interview 1)

When discussing the FA during the pandemic at school, Ruby shared “The only differences, they were removed from the great hall eating to their own classroom. So, much smaller contained environment at that time” (P02, Interview 1) reflecting that smaller eating areas such as classrooms potentially reduced the risk of allergen exposure. Finally, Sandra discussed that having her son at home from school during the pandemic resulted in less stress about FA, sharing “We did online school for a couple of years and we didn’t have to worry about any of this stress dealing with teachers and principals, and classmates knowing about food allergies and stuff “(P09 Interview 1).

Children and Youth

Most children and youth denied that the pandemic had any major impact on their FA experiences at school; however, when asked a few youths did highlight some changes. Anna (age 15) shared that added sanitization and handwashing caused long waits at lunch and moving forward having hand sanitizer when food is served would be helpful. She shared, “It caused extremely long waits for lunch and lines in front of the sink. There were so many kids needing to sanitize. [Hand] sanitizer would work better, just nearby a lunch line.” That said, most children and youth maintained that the pandemic did not impact their FA experiences at school. Katie (age 14) reflected, “It didn’t change. I was kind of normal, like, all other times with my allergy. Yeah, I don’t think wearing a mask didn’t do anything, yeah, nothing really changed (P01, Interview 1). Another youth, Jack (age 16), also succinctly said, “No, it was just, like, the mask thing, but everything was pretty much the same (P21, Interview 1).

Lived Space: Holding Safety in Place

The existential of lived space represents more than just a physical space or geographical location; it reflects one's embodied and felt experience of a space (van Manen, 2014). The theme for the lived space existential is *Holding Safety in Place*. For children, youth, and their parents, spaces are experienced through the lens of safety. This theme captures the everyday experiences of maintaining, striving for, or negotiating safety across environments such as the home and school. Safety in spaces is not fixed or assumed; rather, it requires ongoing vigilance and attention. Once safety is established, care is taken to preserve and sustain it which promotes feelings of safety and comfort. This theme is expressed through two supporting subthemes: *Home Safe Home* and *Navigating Risk Landscapes*. Together, these two subthemes highlight the contrast of how families experience feelings of safety in trusted spaces such as the home and navigate safety in uncertain or less familiar environments. A visual summary is presented below (See Figure 9).

Figure 9

Lived Space



Home Safe Home

The subtheme, Home Safe Home, reflects how the home is experienced as a safe, controlled, and trusted environment for families living with a FA. In the home, safe practices and routines are established and familiar allowing for a shared understanding of safety within the family. This shared understanding and establishment of routine safe practices allow the family to feel a deep sense of comfort and normalcy allowing some respite from the vigilance required when outside the home.

Parents

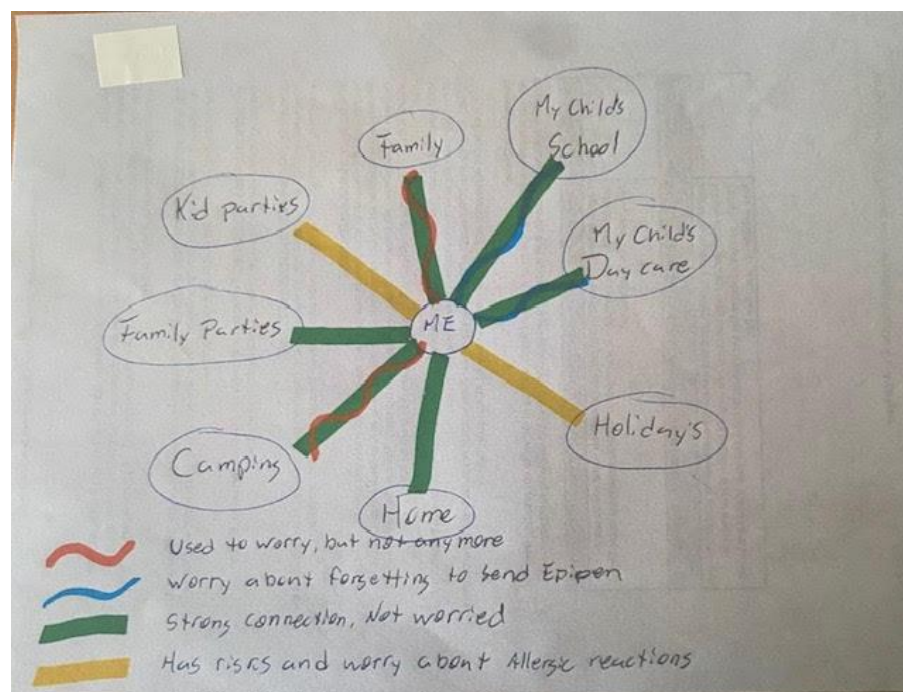
Parents described establishing the home as a safe haven for their child with a FA with the intention of creating a space of comfort and a sense of normalcy for the entire family. In all parent ecomaps, the home was described as a safe space in which FA were not worrisome. In creating this space, families established and adhered to safety precautions and routines within the household. Ruby, mother of a youth with a tree nut allergy described feeling comfortable in her own home, a controlled environment, “Never any concern because it’s under our roof and we feel quite comfortable (P02, Interview 1). For Sandra, whose son has a severe allergy to peanuts, nuts are not allowed in the home. She shared:

We generally, tell people to not bring nuts into our home or eat them. We try to remind people, but this harder to do for the people that eat them. We don’t allow peanuts in the house, like, that is just not something we are, as a firm stand for our family. If peanuts are that important to you, don’t come. I think the main idea is to keep our home as, kind of, the safe sanctuary for friends to come and just have food here. To make this the default, I think it is good on multiple levels. (P09 Interview 1)

Home as a safe space was also depicted in parent ecomaps. The ecomap created by Billy, father of a child with allergies to cashews and pistachios described home where there were strong relational connections and an environment where the family was not worried about food allergy. (See Figure 10).

Figure 10

P15 Parent Ecomap



Another parent, Sarah, depicted the home as the safest environment for her child with allergies. (See Figure 3, p. 98). Similarly, eight other parent participants described their home environment as strong, again indicating the presence of strong relationships and the home was a safe space with respect to FA.

Home as a safe space extended to hosting friends and family, where participants could socialize safely without worry about FA within their own controlled home environment. Sandra explained, “I think the main idea is to keep our home as a safe sanctuary for the friends to come and just have food here. To make this, the default, I think is good on multiple levels” (P09,

Interview 1). Having friends over in the home allows socializing with friends to occur but removes the worry and uncertainty about unsafe foods or cross-contamination that would accompany going out into unfamiliar settings.

Children and Youth

Children and youth described the home as a safe space, one in which they could feel normal and not have to worry about their allergy. Katie (age 14) stated, “At home, I felt a lot safer, like, I could eat anything. I would never have to worry about if anything was safe or not. I would always feel comfortable” (P01, Interview 1). Sally alluded that her parents keep her home allergen free, “they try not to have what I am allergic to in the house” (P14, Interview 1). Anna (age 15) described her home as nut-free but added that if nuts did come into the house they would be stored in a secure area, “My family can accommodate pretty well to it. So, it’s not too much of an issue. Like, my father will have nuts, but he’ll keep them in a separate place away from the rest of the food (P04, Interview 1). Similarly, Darren (age 16) expressed, “cooking at home, never, I don’t think we have any sort of peanut products in the house that isn’t directly locked somewhere so not to get confused with other food” (P18, Interview 1).

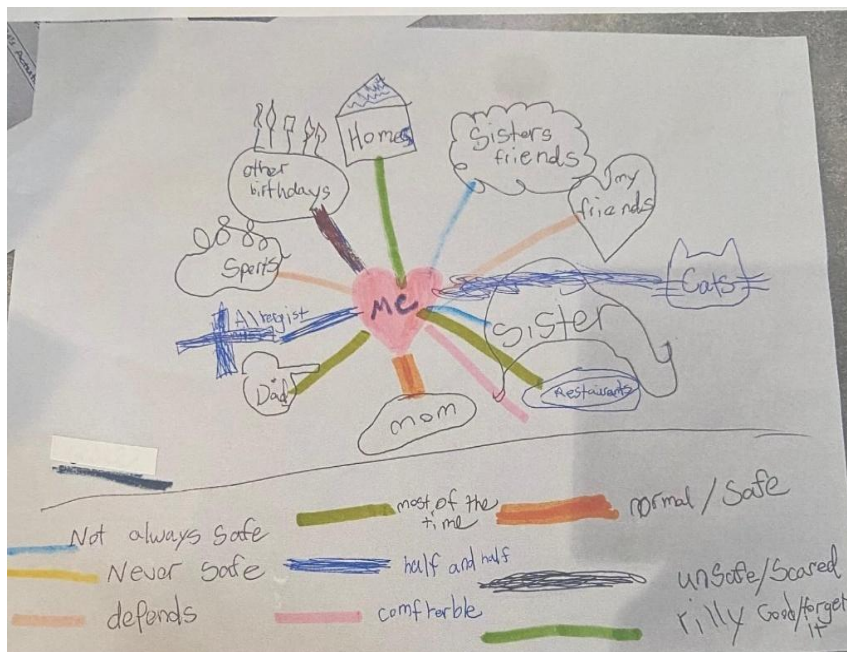
The home was described as a safe environment not only due lack of exposure to food allergens; but also, because home was associated with strong, trusted relationships. Owen (age 10), shared these feelings of safety:

I feel really safe with my family, my mom, my dad, and my sister. I don’t really feel my allergy at home. I almost forget about my allergies. It means that I just forget that they, like, exist. I feel pretty safe because my parents are always by me. There is at least one in the house. (P08, Interview 1)

Anna (age 15) also described feeling safe in the environment of home and in her relationship with close family, “For my ecomap...I felt that I had no safety concerns, I put at home or close family. I don’t really feel any concerns with my allergies” (P04, Interview 1). Claire (age 8) created an ecomap which depicted the interconnection between comfortable and trusted relationships and the home where her FA could be almost forgotten (See Figure 11).

Figure 11

P16 Child Ecomap



Navigating Risk Landscapes

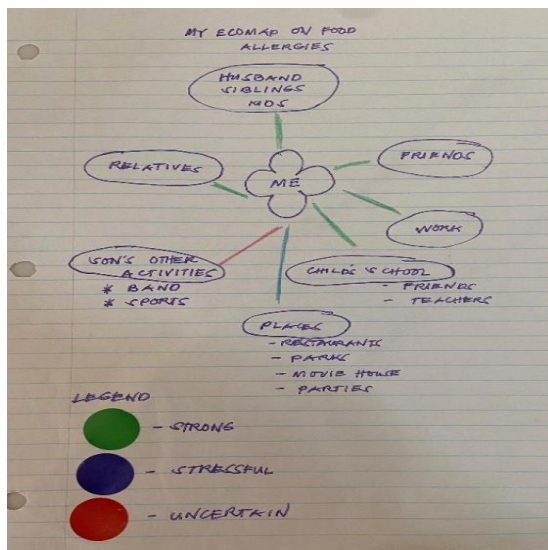
The subtheme, Navigating Risk Landscapes, reflects the lived experience of children and youth with a FA and their parents within various environments where FA safety cannot be assured and navigating safety is necessary. Risk landscapes include environments such as schools, restaurants, friends’ homes, or any environment outside the home where children and youth, and their parents engage in actions to mitigate risks and minimize exposure to the FA.

Parents

Parents identified certain spaces, or risk landscapes, that carried greater potential for risk for their child with a FA. These settings included community venues where extra-circulars or sports took place, social environments for birthday parties or playdates, restaurants and school. The risk landscapes depicted in parent ecomaps reflected variable perceptions of risk. In Melissa's ecomap, she identified environments such as sports and parties that caused stress due to her perceived risk for her son's safety. She did not depict the school as stressful as she conveyed that her son's school adhered to a nut-free school policy (See Figure 12).

Figure 12

P20 Parent Ecomap

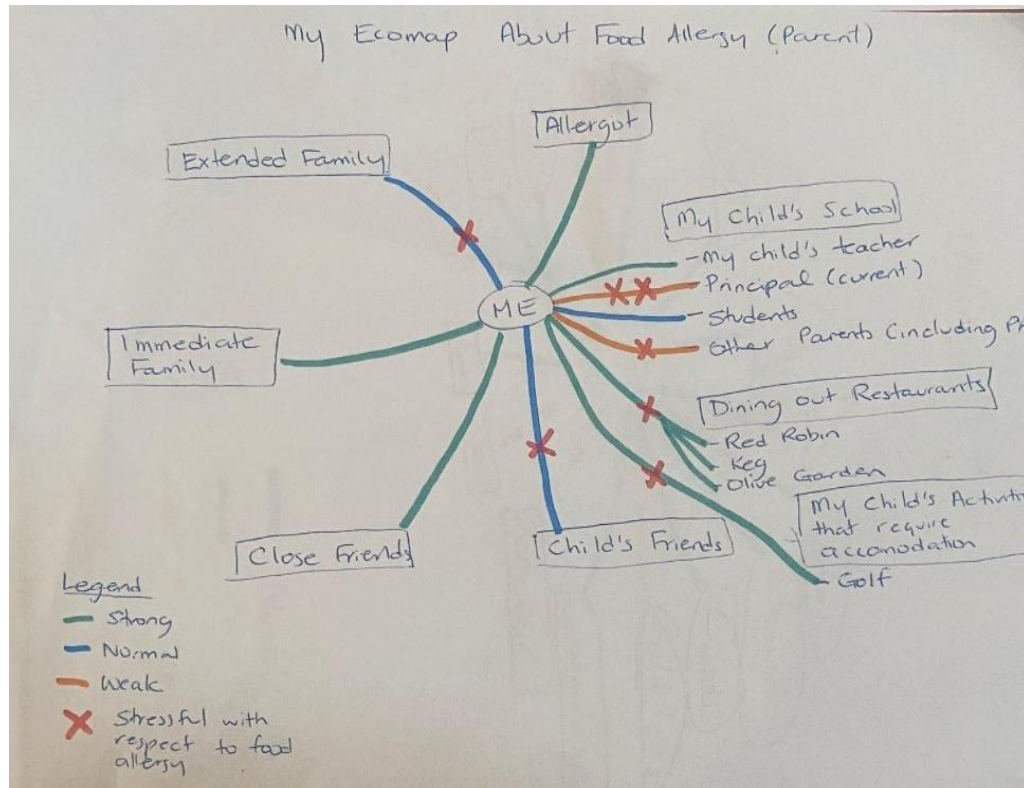


The ecomap created by Sarah (See Figure 3, p. 92) depicted activities and environments such as sports, playgrounds, birthday parties, and restaurants as the most stressful due to the perception of high risk for her son with multiple allergies. Unlike, Melissa, Sarah did identify the school as an environment associated with risk. She described her son's classroom environment as stressful for her and her son, emphasizing that school lunches and field trips were the most stressful for FA safety. Sandra's ecomap also depicted the school, restaurants, and community

spaces as Risk Landscapes. See Figure 12. Of note, her son's teacher and other students at the school were not a source of stress for her; however, the principal and other parents within the school community were identified as sources of stress as it related to her son's FA.

Figure 13

P09 Parent Ecomap



Social events outside the home and school, such as birthday parties and play dates, were often described as stressful due to uncertainty about the food being served and the hosting parents' knowledge of FA. Unfamiliar environments were experienced as risk landscapes that brought on worry and often required additional planning so that their child could safely attend. Parents described proactive measures such as advance communication with hosts about food, FA safety education, and sending safe alternatives to ensure their child could feel included and

participate safely. Ruby, mother of a youth with a tree nut allergy, described this as behind the scenes work. She shared:

Behind the scenes, just calling food companies. If I am never sure, even prior to going to a birthday party, I would text a mom and say, ‘Where are you getting your pizza from?’ or ‘Where is your cake from?’ and doing my own background research to send her confidently to have fun at the birthday party. So, calling companies, speaking to restaurants...It’s time, it’s work, it’s talking to the teacher and trying not to be a burden to the teachers and the parents. (P02, Interview 2)

Ruby also commented on safety measures she took for her daughter:

So, going into somebody’s home, she [daughter] would witness me having education sessions with the parents – asking what they will be serving, where is it [food] from, do you know how to use an EpiPen? She would stand at the door and hear me teaching a parent how to use an EpiPen. I think that does help her make her feel more confident and comfortable in that house. (P02, Interview 2)

Another mother, Linda, described how her daughter’s multiple FAs limited her full participation in some social activities.

The things she can’t do because of this, like, I am never going to drop her off at a sleepover until she is comfortable. She doesn’t go in other people’s cars, she doesn’t feel comfortable. There is a lot of accommodating that. I have to take her places rather than let her go with a friend. And we don’t leave her at birthday parties unless it’s like for a half an hour. I hand over an EpiPen. I give instructions if it’s someone I trust, it’s a lot. (P17, Interview 2)

Sports or other extra-circulars at schools or within the community were experienced as spaces that had potential risk where food or opportunities for cross-contamination could occur.

Sarah shared her experiences and described her son's feelings about group activities:

So, we found out that when we were doing group sports, there was often at the end of the game, shared oranges or a shared cupcakes or Timbits somebody else would bring. And that became stressful for us. Not only did I need to make sure the food around us was safe, but that they weren't cross-contaminating anything. So, he has, actually his own personal decision, just take up a lot of individual sports. (P13, Interview 1)

While Sarah's son decided to opt for individualized sports, Sandra was proactive in pre-screening activities so her son could safely participate.

There were a few activities that weren't very allergy aware. You know you kind of get the glossy eyes 'Oh yah, yah, yah...', but once you delve more into it, they have no idea of how to use the EpiPen. They have got the orange to the hand and blue somewhere else, like, you are going to jab yourself yet, like, that part is frustrating. So, I really do screen activities, especially the ones where he is outside without me around...So, for the activities that [son] is in, they all have really strong protocols, like, receptive to understanding how to treat an allergen and the coaches and instructors are allergy aware.

If they are not, I don't put him in. (P09, Interview 1)

Ruby, mother of a youth with a tree nut allergy, shared her experiences and feelings about a lack of control over cross-contamination and allergen exposure during sport:

Sports is my next one. Practices always felt normal, safe. Events was stressful, team travel was stressful. So, you lacked control. Big one was swim meets for [daughter], and you are sardines in the pool next to one another and not with your child. Everyone has

their own lunch kit and they are left alone and many times [daughter] said there was bags of trail mix or protein bars that she knows has cashews or even bags of pistachios. These kids are sitting very near to her and in the same swim water that they are all bringing into their mouth and spewing it out, made me very concerned. (P02, Interview 1)

She also discussed the lack of control she felt when her daughter was travelling with school sports teams, “Team travel was another one where I lacked control or still do, with school especially. Putting our daughter on a bus assuming people are following the guidelines, but then hearing from [daughter] on return, that is not the case” (P02, Interview 2).

Unfamiliar restaurants were frequently cited by parents as risky and uncertain. Sandra stated, “We haven’t been eating out as much. So, I am hoping that will kind of de-sensitize the fear of going out and trying new things. And then, having a wider range of, like, restaurants that we can go to, to hopefully maybe reduce that level of anxiety [son] would feel” (P09, Interview 2). Nicole highlighted how being at home was safe, but when going out to eat, FA was always a consideration, “I guess it’s always in the back of my mind when we are out at somebody else’s house or when we are at a restaurant. I know our house, it’s safe and controlled” (P19 Interview 2, lines 82-84).

Although eating at restaurants with a FA was often associated with a certain level of risk, clear communication about allergy protocols from the restaurant staff lessened the uncertainty and made families feel comfortable. Cameron gave his perspective:

From a restaurant standpoint, I would say most of the experiences are extremely positive, outside of your fast-food places, which again, you have minimal control. But any nice restaurant that you would communicate, they would be like ‘Okay, I am going to go talk

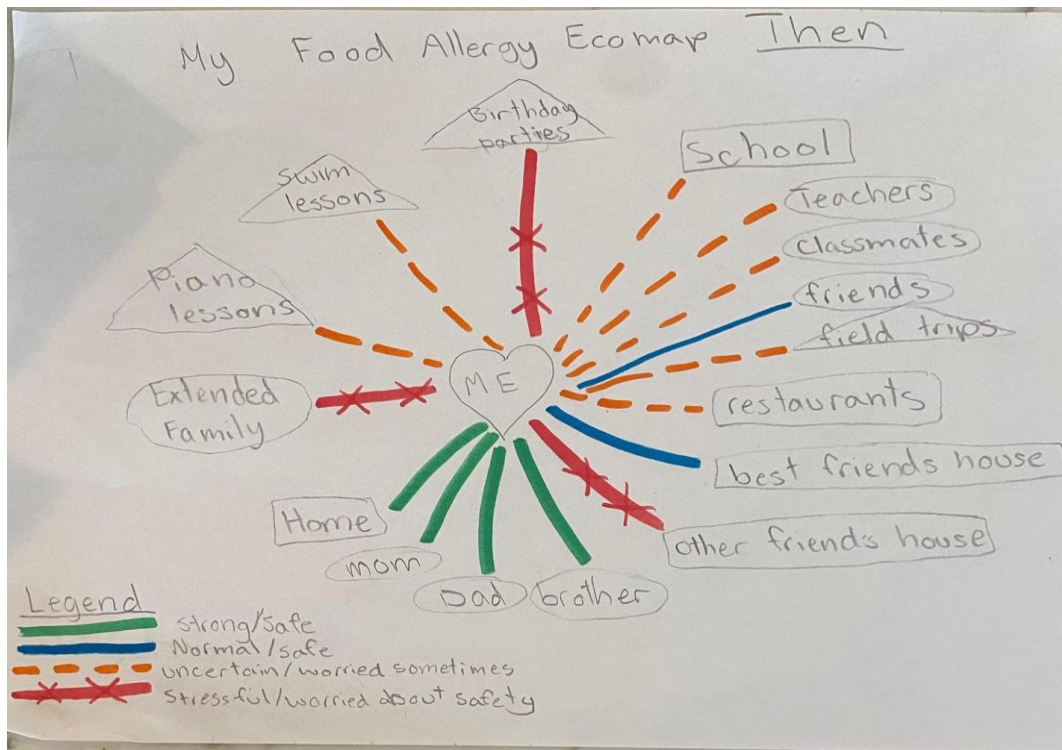
to the chef. The chef would come out a lot of times and just give you that insurance and comfort, which I thought was pretty impressive. (P03, Interview 1)

Sandra expressed, based on her experience, that established restaurants were often very accommodating when dining out. She mentioned that her family has three safe allergen safe restaurants which they regularly visit. When looking for new dining options, they will opt for restaurants that do not have peanuts on the menu. Sandra described that they first preview online menus for allergen lists and/or would call in advance to find out about allergy accommodations before first trying a new restaurant.

The school environment was described by a few parents as a safe space, while most described it as a place associated with a varying degree of risk, stress, and worry. According to parent ecomaps, when strong relationships with teachers, principals, and classmates were depicted, the school was perceived to be safe. When parents depicted the school as has having risk, variable relationships with teachers, principals, parents, and classmates were noted. This is explored further in the lived relation subtheme, setting the tone at school.

Children and Youth

Navigating Risk Landscapes for children and youth were environments outside the home, such as school and friends' homes, where food was present and they were uncertain about others' understanding of FA and the safety of foods. Risk landscapes were illustrated in the ecomaps created by children and youth.

Figure 14*P01 Youth Ecomap-Then*

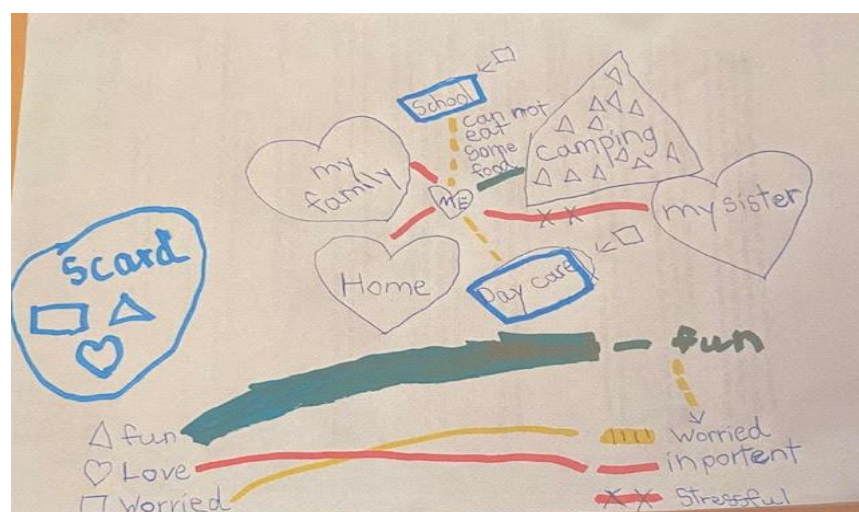
There was a noted distinction of the depiction of safety Katie's (age 14) best friend's house where they had FA awareness and knew about her allergy versus worry when other friends whose families may not have been aware or educated about FA safety. Katie shared her experience of uncertainty of going over to a friend's house and being offered a treat.

I remember going to a friend's house and I got a popsicle, and I asked 'Hey, is this, like, safe, or whatever?' and I am pretty sure they said, like, 'Oh, I'm not sure' or 'Yeah, it's fine'. But there was not label on it, so I couldn't read it and so, I started eating it and then I am like 'Hold up, what if this isn't okay?' So, I started, like, freaking out. But what would make it comfortable was the reassurance, like me going to look at the box or whatever I was eating, making sure I know personally that it is okay because the trust it's hard to trust people if they don't know about the allergy. (P01, Interview 2)

The ecomap created by Jack (age 16) depicted environments outside the home as uncertain or stressful as it related to his experiences with FA (See Figure 5, p. 101). Jack explained that when attending parties, he perceived a lack of awareness about his FA among others, and when dining at restaurants he experienced uncertainty about food safety due to the variety of foods served that could contain his allergens. Similarly, Liam (age 11) created his ecomap according to relationships, activities, and places with feelings ranging from strong or safe to worried and stressful (See Figure 4, p. 99). For Liam, activities and places that caused him to worry about his safety included school, field trips, going away on vacation, or visiting his extended family at their homes. The most stressful activities and places for him included day camps, restaurants, friend's houses, or where birthday parties were held. Claire (age 8) felt safer if snacks were not offered at her sports activities, explaining, "Not everyone washed their hands. Because then, I can get hives" (P16, Interview 2). Sally's (age 8) ecomap depicted environments outside the home which she experienced worry or feeling scared about having an allergic reaction (See Figure 15).

Figure 15

P14 Child Ecomap



Children and youth shared how they and their parents navigated safety in these risk landscapes. Anna shared this about her parents:

They would do that [safe foods] for parties, travelling, and school. For school, they would give snacks they knew I could have and that I liked to teachers when or if there was an event that would involve food I couldn't eat. And for travel and parties, they'd, they would also make sure I had something to eat, especially for parties because a lot of kids would be eating things that I wouldn't be allowed to eat. (P04, Interview 2)

Darren (16) navigated uncertain environments by having the confidence to ask safety related questions and always having his EpiPen on hand in case of an emergency. Liam (age 11) reinforced being prepared going out to different places when he explained that he always brings his fanny pack with EpiPens and inhalers for safety.

For Katie (age 14), there was a realization that trust in the environment was established through frequent visits and where friends and their parents were had knowledge about FA safety.

So, it is hard to build trust if you don't see them that often. You might see them at school, but not the parents, but if you see them a lot, it's easier to gain trust, yeah, over time. If there is more encounters and telling the person about the allergy, it is a lot easier to gain trust. (P01, Interview 2)

Within the school environment, lunch was eaten either in the classroom or school cafeteria for children, while for youth high school, lunch could be eaten anywhere on or off site. Lunch supervision for children at school varied, some overseen by teachers and others relying on parent volunteer or student helpers. Although most schools had nut-free or nut-aware policies, these spaces carried perceived risk as expressed by some children and youth. Sally (age 8) felt safe and comfortable eating in her classroom at school. When asked about what makes her feel

that way, she stated, “because the school doesn’t allow nuts and [teachers] check everybody’s food to see, they look at everyone’s food to make sure” (P14, Interview 1). She also shared that “We wash our hands and at the end of the day someone comes to wash our table for us. We can’t share food unless it’s a holiday or something like that.” However, some children described actively managing their surroundings, such as moving desks or moving away from known allergens to maximize their feelings of safety. Claire (age 8) described creating a buffer space for herself when eating lunch in the classroom. “So, instead of just sitting with my desk group, I move my desk backward, and they get to sit there, and I get to sit back. But back there, but I could still talk to them because I don’t have to move too far” (P16, Interview 1). Owen (age 10) denied that his school had rules about handwashing before or after eating and did not notice that tables were wiped down after eating in his classroom. He did recount an experience where another student brought in eggs for lunch and stated, “It was just a little bit uncomfortable, but I like, just moved away” (P05, Interview). During lunch time, supervision varied from teachers staying in the classroom to supervise while others were monitored by students or parent volunteers.

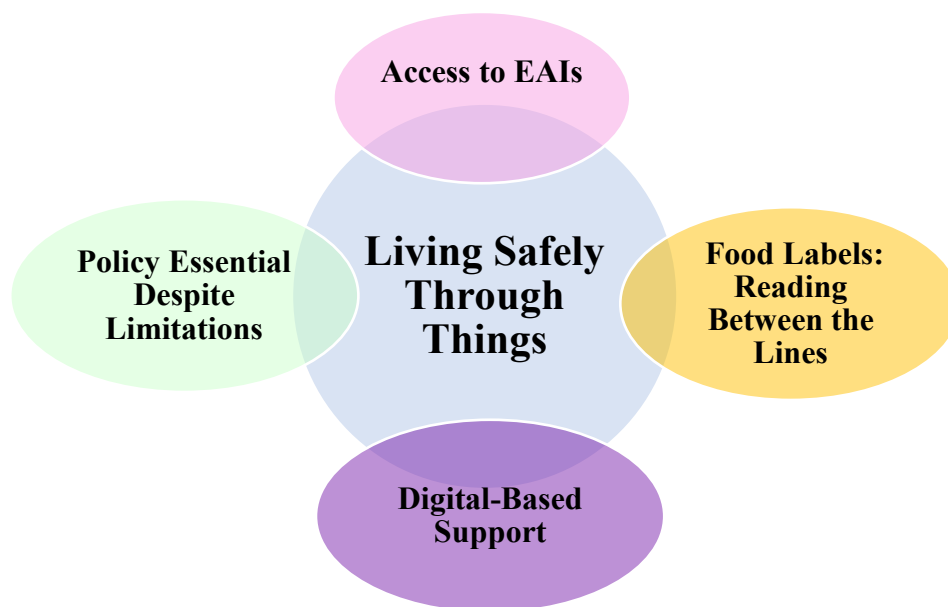
Lived Things: Living Safely through Things

Lived things, is the fifth existential that conveys how people experience and engage with the physical objects, technologies, and the material world (van Manen, 2014). *Living Safely Through Things*, is the theme for lived things in this study. This theme conveys not only the physical things of importance in promoting and maintain both physical but also symbolizes the psychological safety and reassurance they can also represent as expressed by parents, children, and youth participants. Further, living safely through things, helps families with FA navigate risk landscapes outside the home. This theme is explored through four subthemes: *Access to EAls*,

Food Labels: Reading Between the Lines, Digital-Based Support, and Policy Essential Despite Limitations. A visual summary of lived things is shown below (See Figure 16).

Figure 16

Lived Things



Access to EAI's

For children and youth living with FA, and their parents, an EAI represents an essential safety object and having Access to EAI's at all times is paramount to safety and feelings of comfort and preparedness. Parents discussed various locations of their child's EAI (e.g., EpiPen) at school and uncertainty about whether their school kept stock epinephrine for all students. When asked if this should be a policy for schools, all supported this.

Parents

Parent participants recognized the importance of ensuring their child always has Access to EAI's, as well as ensuring those responsible for their child's care were educated on how to use

one. The number of EpiPens required by students with a FA and where EpiPens were stored varied by school (see also Table 5, p. 87). Some schools required only one EAI while others required to self-carry one EAI, with a second stored in the school office. Lynn shared that her son's school only required one EpiPen which "stays in the office", while Sarah's son school required two.

The main office has one EpiPen and the second EpiPen, I was kind of given the choice but in Kindergarten, Grade 1 and Grade 2, the teacher just took it and I didn't really know where it went. I later learned that it was kept in a Tupperware container, somewhere the teacher knew about, but I am not sure if it was clearly marked or if anyone else knew where it was or anything. My son did not know where it was. This year my Grade 3 teacher asked me what I wanted - if they wanted to keep it in my son's backpack or in the classroom or in the locker and to be honest I don't know where it actually ended up. I said not his backpack because it is very temperature sensitive. (P13, Interview 1)

Sandra appreciated that her son's new school policy required children requiring an EAI to wear it on person, "They make all the kids self-carry, which I think is fantastic. Time is of the essence. You don't want the EpiPen in the office. Because in summer school last year, the school staff didn't even know where the EpiPens were" (P09, Interview 2). Parents also shared that the requirements changed as their child got older,

One [EpiPen] in the elementary years, it was supposed to be on them. They did have that little waist, fanny packs that they wore for elementary school. But, then went to the backpack later on. There was a few times where we did provide an extra one in the office. (P19, Interview 1)

Parents had variable knowledge as to whether their child's school had stock epinephrine. When parents were asked about their school policy, none stated that their school stocked epinephrine, some were unsure, while most believed they did not. All participants who were asked whether their child's school should have stock epinephrine at school, all replied yes. Ruby, mother of a youth with a tree nut allergy, stated:

Absolutely [schools should supply epinephrine]. A kid could be exposed to an allergen at school for the first time and for some instances, if you are potentially a smaller school, or don't have anybody with an EpiPen that you would use for an emergency situation, why wouldn't you carry that on site? I think it is a fantastic idea and should be implemented (P02, Interview 1)

She elaborated:

I don't think the cost could be even a question in this, as people would say the cost of the pen, you have to replace every year, they expire. And comparing to an AED, the cost of those units and replacing batteries and educating families on keeping that battery charged, and checking expiries ... and outdated, it's just as easy to get on board with EpiPens. Narcan is covered as a life-saving device and I feel EpiPens should be. (P02, Interview 1)

Other parents agreed. Lynn emphatically responded "They definitely should! They should be matching the children's age, right? It's like one EpiPen in an emergency only helps you for so long, right?" (P06, Interview 1). Another mother of an 8-year-old child added, "The EpiPen is a generic medicine, it is not based on each individual allergy, so that would be wonderful if the school would have their own" (P13, Interview 2).

Children and Youth

For children and youth, having an EAI (e.g., EpiPen) symbolizes preparedness and represents a final safeguard if other precautions fail, providing reassurance and confidence in managing their FA. Having Access to EAIs at school is an essential part of this safety plan. That said, there was variability in the number of EAIs children and youth had at school and where EAIs were stored. For youth in middle or high school, EpiPens were kept in their bags that travelled with them during the school day and some youth had another EAI stored in the office. Anna stated that in high school, “I carry an EpiPen usually on me in a pocket or in my school bag” (P04, Interview 1). Katie (age 14) elaborated:

It’s always in my backpack which I carry around with me from class to class. Sometimes, the odd time, I might not have one, but if I am going out somewhere, to a restaurant or a mall or something, I will always have one with me in my bag just in case. In school, there is always one in the office too. (P01, Interview 1)

Anna (age 15) and Katie (age 15), both shared that in their early years at school, they had to carry self-carry their EpiPen using a fanny pack or belt. Anna remembers being bothered by this sharing, “My main annoyance, I would say, was when I was, like, in Junior School and Middle School, I had to wear an EpiPen around my waist which really annoyed me. That was my main, that was honestly the thing that bothered me the most” (P04, Interview 1). In contrast, Katie shared, “I don’t think I really cared. I kind of owned my allergy. There was another kid in my grade who had an epi-belt too, so I knew how he felt. I didn’t feel self-conscious or anything” (P01, Interview 1). Not all schools had this policy. For Claire (age 8) she was not permitted to use her fanny pack at school. She said, “I am not allowed [to self-carry EAI] ...because they have a [school] backpack that have my stuff in it” (P16, Interview 1). In Sally’s (age 8) school,

however, she was required to have only one EpiPen which she self-carried on her waist. For Owen (age 10), who has a severe peanut allergy, his family opted to keep two EpiPens on person, with a third stored in the school office. Similarly, Liam (age 11) wore a fanny pack with his EpiPen and had another at the office, while Cody (age 12) reported that his middle school only required one and was stored in the office. Not only was having access to an EAI at school required, but it also provided reassurance to children and youth. Darren (age 16) shared, “I always have an EpiPen either on my person or in a bag. So, I’m not ever really concerned” (P18, Interview 1).

Food Labels: Reading Between the Lines

For families living with a FA, food labels on food products can signal if something is safe or potentially harmful. Labels about food allergens can provide a sense of security and reassurance for families that the food they are purchasing and consuming is safe at home, in the community or in the school setting. Similarly, they may provide clear guidance to avoid products containing known allergens. However, precautionary allergen labels (PALs) on foods with statements such as “may contain” or “processed in a facility” leads to uncertainty and shifts the burden of decision making on parents, caregivers, and children or youth to determine what is safe. Reading a food label extends beyond simply scanning ingredients; rather, it becomes an interpretive exercise in assessing risk. Families are often forced to make a judgement call based on previous knowledge and experience resulting in a variable approach to consuming products with PALs. While food labels, including PALs, are not specific to school environments, these labels are relevant within school contexts, where children and youth may be required to independently make food safety related decisions. Parent, youth, and children experiences with “may contain” labels are explored below.

Parents

Parents of children with a FA are tasked with making decisions about food safety when reading food labels that include PALs such as “may contain” or “processed in a facility/factory.” These decisions are informed by guidance from their allergist and by prior knowledge and experience with certain food products and manufacturers. There was wide variability in how families interpreted labels with precautionary statements, and several examples are highlighted below.

Some families initially did not allow foods with “may contain” precautionary allergen labels to be consumed by their child with a FA, but over time and with education and experience, “may contain” food products were introduced. For Sandra, whose son has a severe peanut allergy, “may contain” products were determined to be a “hard no.” Cameron, father of a 14-year-old youth, explained his evolving perspective over the years:

I think as we got further on in the process and as she got older, we became a little more relaxed if it said ‘may contain tree nuts’. Before, it was absolutely not. Now, as we learn and [wife] educates us more on it, it’s just because there is probably like, and she’ll phone some of the manufacturers if it says it may contain tree nuts and they say, ‘We have to put that on there,’ So, it’s kind of like, why put it on there? There is probably zero chance that it’s on there. (P03, Interview 1)

Nicole’s allergist recommended against eating foods with “may contain” food labels for her sons. She and her family followed this advice when they were younger, but over time gradually introduced “may contain” food products in the house.

He [allergist] was the one who, at the beginning of our journey had said, like ‘Nothing may contain, nothing that’s in the same factory as it’ So, we were pretty diligent at the

beginning of nothing unless it had that nut free or peanut free label right on it and just educating everybody else, ‘Sorry, this candy is not safe or this cake from the store is not safe. We started to allow, like [son] said, eating things that ‘may contain’ because we’d read through the ingredient list and peanuts wouldn’t be there. And you’re supposed to trust Canadian labelling laws, so if it doesn’t say, but, we didn’t usually do the ones that were processed in the facility that also makes peanuts. (P19, Interview 1)

John, father of a son with multiple food allergies, provided another example of an evolving perspective of “may contain” foods. He explained that their family initially avoided them entirely, then gradually permitted some to provide their son more food options but then returned to strict avoidance after an anaphylactic reaction prompted them to reconsider the level of risk they were willing to accept.

But, then he did before. So, we would give him sometimes ‘may contains’ because it was, like, couldn’t eat anything and he was always left out. And then, we get ones where there’s no nuts in the ingredients, but they ‘may contain’ because it comes from a not a peanut free factory. So, we would let him have those. Then the allergy [anaphylaxis] happens and then, now we’re hypervigilant again. (P12, Interview 1)

Some parents reported taking a different approach to “may contain” depending on the circumstance. Andy shared that initially they avoided all ‘may contain’ products but now allow them under their direct supervision. He explained:

At this point, if it says, ‘may contain’ and it is in our household, we allow [daughter] to have it. If it says, ‘may contain’ and it is somebody else’s household, we advise them not to. Basically, [wife] and I will accept the risk, but we don’t want to put that risk on other people. (P15, Interview 2)

Another parent, Melissa, stated that she avoids foods with PAL such as “may contain” or “processed in a facility” for her son, unless she has first-hand knowledge about the facility’s procedures. She explained her perspective:

No, I wouldn’t give him that. But at my work, since I used to work in the bakery, I know if that product has been made on a separate table. For the cake, we will put it ‘may contain nuts’, but I know there is no nuts on the table. Like, we are using three tables in the bakery there. So, something like that, if I am aware of, but like if it’s from another bakery, then no I wouldn’t. I wouldn’t take the risk. (P20, Interview 1)

Linda shared her perspective on how she approached “may contain” products in their household. She explained:

I will check with the anaphylaxis group. If it is a product that was questionable, she won’t eat them anymore, unless it’s something she has had before. Like her favourite cereal is a ‘may contain’ peanuts. It’s like Enviro-Kids, I think, and she has been eating that her whole life. So, she’s fine with it. But, if she wants to eat a new product and it does say ‘may contain’, she won’t touch it (P17, Interview 2)

Sandra’s comment captured this variability amongst families, stating, “So, it taught me that not everyone with a food allergy thinks the same. Some people are okay with eating ‘may contain’ and some people are not, and I think it’s totally okay too” (P09, Interview 2).

Children or Youth

Children and youth described varying and shifting perspectives on “may contain” PALs on food products, often aligning with their parents’ approach. Anna (age 15) reflected on her shift in approach to “may contain” products. Anna began by saying, “She [mother] doesn’t really buy products that say, ‘may contain’ nuts and usually avoids ‘may contain’ products” (P04,

Interview 1). She went on to explain that “I am now comfortable usually with products that say, ‘may contain’. When I was younger, I didn’t really know what it meant and just listened to my parents when they told me I couldn’t have them.” Anna elaborated further:

Well, I realized that a lot of products that say ‘may contain’ are just manufactured in a factory that just happens to make some products that do have nuts, so, I am fine with a lot of ‘may contain’ pre-packaged products. I am usually more cautious at restaurants or places where I think nuts could be in close range or where it would actually be a concern.

She also talked having to make a judgement call about product safety, indicating, “I check product labels pretty frequently and usually use my judgement if I have something that says, ‘may contain’ or not depending on the type of product”. Darren (age 16) also shared his approach to “may contain” food labels, indicating, “It depends on if I have ever had them before. Like, if it’s something new, I would stay away from it. But, if it’s something that I am certain I have had before, I would eat it” (P21, Interview 2). He went on to say that,

My Mom taught me that if it says, ‘may contain’ peanuts, most of the time it’s fine, but, yeah, I eat products that ‘may contain’. I just draw the line at, maybe, in a factory that produces peanuts, [then] I wouldn’t eat it.

Another youth shared that as she has gotten older, her allergy has become less severe, she has become less strict about foods with “may contain” precautionary allergen labelling. She shared, “It was different when I was younger because it was more severe and I was more cautious about it, what I was eating, and making sure that everything was safe. If it said, ‘may contain,’ I couldn’t eat it” (P01, Interview 1). However, she is currently comfortable with “may contain” products indicating, “Now I do eat things that say, ‘may contain’ because I feel more

safe about that and I know it will be okay if something does happen as I know how to deal with it.”

Digital-Based Support

The subtheme, digital-based support, refers to the use of internet-based tools and resources including online searches, allergy-specific websites, and online support communities (e.g., Facebook) that parents accessed to help them manage FA safety. Facebook FA groups were highlighted among mothers as a valuable resource and support.

Online resources about FA provided supplemental information and support for some families. Linda, mother of a child with multiple FAs, shared that in addition to the education she received from the allergist, she accessed information from FA websites and her online support groups (P17, Interview 1). For Nicole and her family, the allergist was their primary source of information and used online searches for additional support, sharing “So, I guess it would have just been the allergist giving us most of the information and then after that, just reading online” (P19, Interview 1). Sandra discussed accessing allergy information cards to use as a FA communication tool at restaurants. She explained:

We downloaded the Eco Eats cards, which...list your allergens and everything and you just give it to your server. We used them [on vacation]. We printed out 5-7 cards and gave it to the server and they were like, ‘This is amazing’ because we usually have to ask all the questions or they don’t remember to ask. They bring it to their chef and the bring it to their manager, like a great way to communicate and advocate. (P09, Interview 1)

Online support forums (e.g., Facebook FA groups) offered access to information and resources, an environment to ask questions, and offered important connection and sense of community for its group members. In this study, all online support groups identified were

accessed by mothers. Fathers, children or youth did not share that they engaged with online support groups. Sandra, mother of a child with a peanut allergy stated, “I would say mom groups, food allergy groups, are mostly moms, the majority, 99% are mom, and through those Facebook groups” (P09, Interview 2). As a source of education, Sarah shared:

Most of the information I have found support through a Facebook group. It might be through the United States, but it’s called *About Food Allergies*, I think. I don’t remember what the actual name is. There is a wonderful administrator who has wonderful access to links on how to use EpiPens, and there is a huge community of parents who are constantly asking and supporting each other. You know, like, ‘I had to use the EpiPen today and this is our experience,’ and it’s been my most, to be honest, my most education. (P13, Interview 1)

These types of Facebook groups not only connect parents to share knowledge and resources; it also provides a sense of community and support. One mother of a child with a nut allergy, expressed:

I told you in the past, I joined, Facebook Food Allergies Mom’s group and that helped me feel a little bit of peace. Some of the questions I may have had in the past come up as topics of conversation. So, just getting knowledge through other people has been helpful and helped me find peace with it. (P13, Interview 2)

In the early years of navigating FA, another mother, Nicole, also spoke of the support she received from Facebook groups:

I joined some FA, like peanut allergy groups on Facebook and stuff, so it was sort of networking support. And then just through conversations, like, realizing that, you know, friend’s children also had it too. So, it was just, never, I never needed to do or speak to a

therapist or counsellor to get more, to feel more secure about it, but just reaching out to other community sources, I guess, would be to, what I probably did. (P19 Interview 2)

Parents described recommending online support groups when meeting other parents of children with a FA.

Oh, I just think the Facebook page, the ...anaphylaxis group is, like, a really big support and it's nice, to, like, I would recommend that to anyone. Actually, I recommended to one of my friends when her son was diagnosed with a nut allergy and, like, 'Oh, you need to join' and get, you know, just a little bit of group think on certain issues. (P17, Interview 1)

Overall, the mothers in this study expressed that Facebook groups were a helpful support tool that provided them with FA education, resources, emotional support, and a shared sense of community with others navigating similar experiences.

Policy Essential Despite Limitations

The last, subtheme, Policy Essential Despite Limitations, reflects the perspectives from children and youth with a FA, and their parents that school policy is of paramount importance and integral to safety within the school environment despite acknowledged limitations. School policy as a lived thing, reflects a written document that demonstrates a commitment to students in creating an environment of safety. Policy documents may be paper-based and/or online documents created by an individual school or shared by school division that guide actions about FA safety and management within the school environment. Overall, families expressed a realistic awareness that policies cannot guarantee safety but does offer reassurance of a school's commitment to promoting safety, minimizing FA risks, and preparedness to respond to anaphylaxis. While participants referenced several school policies such as no food sharing,

requirement of EIAs, and emergency action plans (EAP) updated annually for students, a school's nut-free policy was emphasized most prominently. Middle and high school schools were described as environments where nut-free policies were more difficult to enforce. Gaps between policy and practice such as lunch monitor training, bake sales, and policies inclusive for all students with FA were identified and will be explored below.

Parents

FA Policy Essential. School policy about FA was articulated as an important element in creating a culture of safety and inclusiveness at school which promoted feelings of comfort for parents, despite limitations such as lack of enforcement. From Sandra's perspective, school policies have a large influence within the school environment, stating, "...the policies have severe, a serious impact on how things are carried out day-to-day at school" (P09, Interview2). Melissa shared that she didn't worry about her son at school because she perceived that the school had implemented strong policies, stating, "because his school is peanut-free, I didn't have to worry about it" (P20, Interview 1). Andy also shared his perspective that his daughter's school had a strong commitment to FA safety, "overall they give us confidence that it is a nut-free facility, so we don't really have to worry about exposure in the school because it's on everybody's mind at school" (P15 Interview 2). Sandra described the importance of having standardized school policies. She asserted, "Yeah, it's good to have policy so that parents can use it to back up what needs to be done, especially in cases where you have non-compliance or non-communication" (P09, Interview 2). She further expressed her belief about having strong policies in place at school:

I think to know what is the expectation, to know what's going to happen. I think having a standard policy in place gives parents some kind of measure of assurance almost. Having

a good policy, that assurance that this is something that is being taken seriously, that there is a protocol, there is some thought to it rather than leaving it up to individual principals which varies a lot even with a policy in place. And so, having the anaphylaxis framework in BC, you know the policy is great, but the adherence again is a big issue. Another mother of a child with multiple food allergies also explained that the implementation and adherence to strong FA policies at school contributed to her sense of comfort, noting, “I feel more comfortable than I do most places I send her” (P17, Interview 1).

Policy a Factor in School Choice. The presence of comprehensive and established FA policies influenced decisions about school selection for some families. Anna (age 15) shared her parents’ perspectives in choosing a school which highlights the importance of clearly articulated and enforced FA policy,

I am pretty sure the nut policy was actually the deciding factor in choosing what school I went to in the second grade. We were debating between two schools, and I believe one of them had a better nut policy than the other (P04, Interview 2).

Linda described that actively seeking out a school that she felt had strong and enforced FA policies to help ensure her daughter’s safety. She also noted small class sizes as important in her choice of school for her daughter. She recalled:

I screened a couple of schools, and I needed one that was nut-free. So, at least eliminate one of her allergens. I have never seen dairy free. That’s just, not an option anywhere, right? And then they were just really supportive. And I also wanted a private school, so it’s smaller classes, less bullying, and less kids to, like, have their hands in her face (P17, Interview 1)

Another parent chose her son’s school after meeting with four principals and exploring their policies about FA. She reflected on this process sharing:

Before [son] went to school, I actually interviewed four different principals within the school [district]. We had four choices that I wanted to try. So, I booked an interview with each principal to ask them about their allergy protocol and what would they do if there is an allergic reaction. I noticed a big discrepancy on what each one said. (P09, Interview 1)

Ultimately Sandra chose a school after speaking with a principal who conveyed empathy and confidence in the school's FA safe practices, despite it being a farther distance away from home. It is important to note that while some parents were able to choose where their child attended school, others had no choice but to enrol their child in the public school within their local catchment area.

Potential Impact of Removing Nut Bans. The importance of FA policy was also highlighted when parents were asked to consider a scenario where nut bans were no longer in place at school. Parents described that allowing nuts at school again would cause anxiety. When asked, Marth stated, "It would be a shame if they got rid of the ban" (P17 Interview 2, line 277). Martha spoke speculated that removing the nut ban in school would impact her comfort and stress indicating, "Definitely, that anxiety, right? And that worry, even though he is pretty responsible and careful, of course, that risk of cross-contamination or when kids aren't always making sure they're hands are clean. Yeah, that worry would definitely be there" (P11, Interview 2). John, echoed this sentiment,

Yeah, that would cause a lot of anxiety. If they took that policy away, then obviously it would put a lot of kids in danger. I mean, it would put in danger because kids are high fiving each other and being in close contact all the time, so it would put them at a lot of risk. (P12, Interview 2)

For one mother, eliminating nut-free policies would result in her son not being able to attend school, emphatically stating, “I would home school. Absolutely. Or find a different district. Surely, surely it can’t be all the districts that would do that. And I would, for sure, be sitting outside my MLA’s office day and night” (P09, Interview 2). She also stressed the need to advocate for maintaining nut aware policies in school and reflected how a reversal of policy could have school liability issues should a student experience anaphylaxis as a result.

It’s concerning when, I am sure there are districts who are looking to not have it [nut-free policies]. And I think that is where parents need to stand up and be vocal. Screw the diplomacy. We are talking about, like, they are opening themselves up to a huge liability should anything happened. (P09, Interview 2)

Enforcing Policy. While parents agreed about the importance of school policy, some raised concerns about the school’s ability to ensure that the policies are consistently followed and enforced. Ruby noted that policies are only as effective as their enforcement, stating:

I think there needs to be policy, but it’s one thing to say we have a policy in place, that we are a nut aware school, but is it following through? And again, I think that’s a check box, that’s accreditation. ‘Yeah, we are crossing our t’s and dotting our i’s’, but I lack faith in it being followed. (P02, Interview 1)

Her husband, Cameron provided his perspective:

The rules are only as good as those enforcing. I believe it’s not an issue until something bad happens and a reaction will occur, and more attention will be given. Again, it’s only helpful if the parents are on board and will try to follow the rules. I don’t think it’s the school’s responsibility. They can try their best to give the information. I feel there’s two components to this: education and social responsibility. Yes, we can control the education

they receive, but we can't guarantee that the social responsibility component will be followed. (P03, Interview 2)

Sandra recommended setting up a process in which a lack of adherence to school policy can be safely reported without consequence, sharing, "I think there should be an enforcement of policy and when it's not working as intended parents should be able to have a mechanism, a whistleblower protection, in reporting that" (P09, Interview 2).

School Bake Sales. Schools with nut-free policies that permit bake sales may create conditions that are inconsistent with the intent of reducing risk for students with FA. Despite a school's request that bake sale items are to be nut-free, foods prepared in uncontrolled home environments may include unrecognized nut or other allergen exposure and cross-contamination. Only one family expressed trust in school bake sales and shared:

Well, they [bake sales] are always nut free. And our trust level may be is a bit high, that we trust everything is nut-free. When we say it is and we do check. She does purchase it at school and will eat bake sale items that have brought in the school. (P15, Interview 1).

A mother of a youth with a tree nut allergy shared her experience as a volunteer at school bake sales, highlighting the risks and near misses that can occur.

There is no control of that [presence of nuts]. You can have it written on any poster, any email that this is a nut-aware school and no baking should be brought in. However, being a volunteer at that event, we had to remove bags of baking and remove it from the facility because it was peanut brittle, and it was walnut...bags of nut baking what was obviously missed and thankfully removed. But you have no control over the situation because...was the bowl cleaned out well enough, the peanut butter before they mixed their brownie batter of what have you, I think it is a scary situation. However, as a parent, I am the one who makes

that choice if my child can take part in that bake sale. So, she, [daughter] always knew, no I am not able to take part in that and she knew I would go and get her something or make something at home so she doesn't feel left out. (P02, Interview1)

Middle and High School Considerations. There was acknowledgement about some of the practical limitations of a nut-free policy in middle and high school, in part because of the loosened restrictions on where students can eat and the ability of high school students to leave school premises during the day. Sarah explained:

So, a nut ban would be fabulous, and more education would be fabulous, however, when the middle school children are eating their lunches, it is not a contained room in any way. They are allowed to go outside, they are allowed to sit in the stairs, in the hall. They are allowed to sit in the classroom, so it's kind of like high school in a way. So, I don't feel like there is a way they could control it if they don't have a controlled sitting down atmosphere and I don't know how they could make a policy for the school. (P13, Interview 2)

Other parents of youth noted that there limited supervision at the high school level and that students with a FA need to be responsible for their own safety. Nicole noted the differences in high school. Nicole shared, "In the middle school and high school years, that's when there's just more or less no policy at that point and that's were the kids just had to look our for themselves."

She elaborated on her differences between junior, middle, and high school, sharing:

High school culture is completely different. You fill out forms at the start of the year that are, you know, what are your parent's phone numbers and where do they work and oh, you still have allergies? If you have allergies, do you have an EpiPen? Where do you keep it? That's really all they want to know. They don't dive any further into any of those. (P19, Interview 2)

Lunch Monitors' Lack of Preparedness. A policy-to-practice gap that was identified was a perceived lack of preparedness by lunch monitors or those who serve lunch at school. This gap refers to the disconnect between school policy and practice in FA and anaphylaxis management. Lunch monitors may be overlooked in training leaving them unprepared to recognize or respond to allergic reactions posing a risk to students with a FA. Participants in this study noted wide variability in supervision for elementary or junior school students including older student lunch monitors, paid or volunteer parent monitors, and teaching staff. Often, volunteers did not stay in one classroom; rather they went from class to class. Ruby, noted her experience as a parent volunteer lunch monitor, "They were never in the classroom the entire time. They roamed or we roamed to least twelve classrooms" (P02, Interview 2). When asked about whether lunch monitors received training about FA, she replied "None. I have often thought 'Oh my goodness'. Well, I know what to do, but does anybody else? And we were lucky if there was a teacher, they didn't have to stay on the floor. I often thought of if something went sideways". Similarly, Linda expressed concern about giving responsibility to older students during lunch sharing:

I don't know if there's any supervision at the Grade 3 level. I think the younger classes, they have, like, an older student in there. I know last year I had an issue with it because she lost her EA and I said, 'Who's going to be in the class if something happens?' And they said 'Oh, there's going to be a grade six or seven student in there' And I'm like, 'You are going to put a child responsible, like, in charge of my child?' That's a problem. So, they need to be aware that this is a potential issue here. (P17, Interview 1)

Sarah echoed these concerns sharing her experiences with her son's school:

One concern I have is that they don't have an adult monitor during lunch hour. So, they either have Grade 5's or if Grade 5's are away, they have the Grade 4 monitoring the classroom for the children eating. I do know there are parents that are paid for lunch-time monitoring, but they are not in the classroom. They are just walking up and down the halls. Yes, there might be two adults that walk the halls and they go outside with the children for recess. I am 99% sure they are not [trained]. I've had some Grade 4's and 5 children, as my own daughter, as well, as a lunch monitor, and no, they were not specifically given any training (P13, Interview 1)

Concerns were also raised that parent volunteers or paid staff working in hot lunch programs in larger settings, such as cafeterias, may not have access to information identifying which students have FA. Ruby, articulated:

In the great hall where they eat lunch and have hot lunch, there is no signage, no listing of names with kids who have allergies. Hot lunch program are run by volunteers who also, although so and so is being fed a vegan diet, we don't know if that child is choosing to be vegan or has a dairy allergy or are they celiac? There is so much potential for error and it's a different parent running the program every single day. There is no highlight of any kids' name who has an allergy in the school, and I find that very concerning. (P02, Interview 1)

She further shared her concerns about a lack of training of parent volunteers about FA safety:

And my other thing with volunteering is now, working with the hot lunch program is – it's fast, it's a mess, you are shovelling all this food out to kids. The gluten free looks very similar to the regular pizza crust and I have witnessed the kids getting the incorrect thing. This could be very detrimental. As parents, we don't have food safety [training], we are

volunteers. We are not trained and while some of us a little bit more hyper aware, if they don't have a child who is experienced in this, I don't know if the same of worry is there, if you give the child the wrong product. (P02, Interview 2)

More Than Nuts. Many parents, including those whose children had nut allergies, raised the issue that school FA policies focus primarily on nut allergies and do not appear to adequately consider other allergies. A father of a child with an egg allergy shared frustration that his school seemed to only focus on nuts, stating, "Come on guys, there is more allergies than just nuts!" (P07, Interview 1). Another parent of a child with multiple allergies asked,

Why are nuts the only food that is being asked not to bring? I wasn't trying to advocate that the entire school need to stop bringing in all of my child's allergies to school, that is unrealistic. However, I was wondering why in the past we had other foods other than nuts asked not to bring. So, that was kind of concerning. (P13, Interview 1)

Ruby, mother of a youth with a tree nut allergy posed the question, "How do we make everybody safe and not just hone in on nuts?" (P02, Interview 1). Parents appeared genuine in concern to make the school safe and inclusive for children with all types of FAs.

Overall, parents expressed that FA safe policies at school were important and provided comfort and reassurance at school despite acknowledged limitations. Limitations included challenges with adherence to FA policy, difficulty maintaining policy adherence in middle and high school environments, lack of FA training for those supervising children during lunch hour, and concern on the emphasis on nut allergies with limited consideration of other allergies.

Children and Youth

When discussing school policy with children and youth, the term "school rules" was used intentionally to ensure clarity and age-appropriate understanding. Overall, children and youth felt

safe in their school environment because of the established safety rules at school such as no nuts, no food sharing, and promoting hand hygiene. Like their parents, they acknowledged limitations to school rules such as nuts still being present on occasion at school. Youth noted that FA bans were often absent in high school and, when present, were difficult to enforce.

School Rules and Safety. Overall, children and youth with peanut and/or tree nut allergies articulated that they felt safe and normal at school because their school had nut-free or nut-aware policies, or school rules, in place. Sally (age 8) stated “You are not allowed nuts at school and that make me feel safe that we are not allowed to have nuts and no one has nuts” (P14, Interview 1). Owen (age 10) also said he felt safe in his classroom with his teacher and classmates, although he did worry about the presence of nuts in other classrooms outside of his.

Children identified other school rules that were implemented at school, including hand hygiene, washing tables, and no food sharing. Hand washing before and after snacks or lunch was commonplace, as was the implementation of a no food sharing rule. Washing tables, or wiping down surfaces, was more variable. Liam (age 11) indicated that tables in his class were not routinely cleaned. However, Claire (age 8) shared that her teacher wiped down the tables after eating, while Sally noted that tables were washed at the end of the day. Another child, Owen (age 10) indicated that his classroom implemented a ‘clean-up crew’, where alternating groups of children were given spray bottles to wipe and clean the tables after lunch and snack.

Lack of Adherence to School Rules. Children and youth witnessed the presence of nuts at school, despite their school’s nut-free or nut-aware policy. Katie (age 14) shared, “although it does say, like, nut-free, they say no nuts, there are people who still bring nuts to school” (P01, Interview 1). It was her belief that the presence of nuts in the school in these circumstances was not accidental, sharing:

I think they know they have nuts, like, they purposely have something in their lunch with nuts, they just don't really care or about the other people with nut allergies because they don't understand or they are not friends with them. I don't understand how they don't get it, but the people without allergies or parents have gotten emails to know, like, 'Hey, this is a nut-free school. Please don't bring nuts or anything with nuts'. But people still do because they either don't see that it has nuts or they just don't really care and just throw it in their lunch kit and be like, 'Oh, whatever'. So, it's kind of hard when they do say it is a nut-free school, but people still bring things that are not nut-free. (P01 Interview 1)

Jack (age 16) with multiple FAs, expressed his general concern over allergens present in his school stating, "Yeah, just kids bringing in foods that are a risk to my allergies" (P21, Interview 1). Normally feeling safe at school, Sally (age 8) expressed worry when other parents would forget about allergies and send nuts in her classmates' lunches. She shared:

I am worried I am going to have an allergic reaction because, I am not worried all the time because you are not allowed nuts at school and day care. I am not that worried, but sometimes my classmate's parents forget. They ask that person if there is nuts in their lunch. And if they say there is, then they move that person to a different table away from everyone else. (P14, Interview 2)

Finally, Anna (age 15) shared that from her perspective, teachers in her high school did not appear overly concerned when nuts did show up in the classroom, indicating, "I have seen some [students] with nuts and the teacher said 'Oh, that's not allowed', but didn't really follow up with anything. (P04, Interview 2)

Bake Sales. A few youths also shared their hesitation to consume foods sold at school bake sales. Liam (age 11) opted not to purchase anything from bake sales due to the uncertainty

about its safety. “I don’t think I can buy things at the bake sale. I don’t think I would buy there because, you know, I am not sure about things. (P10, Interview 1). Although Darren (age 16) did purchase food at bake sales, he opted not to consume the food himself indicating, “I bought things at bake sales, but I never actually eaten it. I usually just buy stuff and give it to my friends (P18, Interview 1). When asked, another youth, Jack (age 16) shared that his school did not have bake sales (P21, Interview 2), while Anna (age 15) explained her approach to bake sales:

My parents never let me buy anything from bake sales. Even now, I always avoid purchasing at these things. Unlike restaurants that have guidelines, foods prepared in the home have no guarantees, you can never know for sure. Even if they are told to send nut-free products for a bake sale and you ask them, they will say there is no nuts but may not realize about cross-contamination. I can’t trust that they know how to read food labels about ‘may contain’ products or clean things properly. Also, why do schools even have bake sales, this seems risky. (P04, Interview 2).

High School Considerations. When reflecting on experiences in middle and high school compared to when they were younger, many youths acknowledge the difficulty of managing and enforcing a nut-free or nut-aware policy in their current school environment. One issue that was noted, was that high school students often leave school grounds to get lunch and come back.

Katie (age 14) reflected,

It would be harder in the older grades, like middle and high school, because they are going in and out. It is really hard. And like, from the stores down the street, they’d, they would go and get a peanut filled, like, ice-cream or like, a Reece’s or something like that to school. And then they are just, like, eating at a random table and then move on to the next class, so, it’s really hard to police that. (P01, Interview 2)

Anna (age 15) had a similar observation:

The not bringing nuts to school isn't very effective because one, nobody really cares to do anything about it or notices and, two, there is a store very close to the school that sells lots of products with nuts, so even if students don't take from home they can still just walks two minutes away and get some. (P04, Interview 1)

Jack (age 16) added his perspective about the management of FA in his high school, "There is not really a restriction for what people are allergic to. But, like, I don't think they sell anything with nuts in the cafeteria" (P21, Interview 1). According to Darren, his teachers at school would not be aware of his FA, nor would his classmates. On school policy, he shared, "I think we just need to write on a form during halfway through the year of where you'd keep the EpiPen, that's about it" (P18, Interview 1). Aside noting that the food served at school was nut-free, he indicated "other than the actual cafeteria food, there is no policy." There was consensus by the youth participants that the responsibility for FA safety in the high school environment was primarily theirs to bear.

Overarching Theme of Study: Striving for Safety

Striving for Safety emerged as the overarching, central theme of this study. Grounded in the lived experiences of children and youth with a FA, and parents, this central theme reflects a continual orientation towards emotional, social, and physical safety in all relationships and within all environments. This orientation towards safety is demonstrated through the daily practices, routines, and decisions made by families to prevent an allergic reaction across environments such as home, activities, and school whilst also navigating relationships with variable degrees of trust and connection all of which shapes their sense of self. School communities also share the core tenet and commitment to creating a safe and inclusive

environment for those with FA. School principals and teachers reinforce the collective responsibility of safety and set the tone through clear communication, establishing and adhering to FA policies which promote safety and inclusion. See Figure 17 for a visual summary of the presentation of results according to van Manen's (2014) five existentials.

Figure 17

Lived Experience of Children and Youth With a FA, and Their Parents



School Policy Recommendations from Children, Youth, and Parents

Parents, children, and youth were asked to share their insights about FA safety in schools and provide their recommendations to help create a school environment that was safe and inclusive for families with a FA. As many of these recommendations were threaded throughout the findings, a table summarizing recommendations is provided below (see Table 8), then highlighted again for emphasis and clarity.

Table 8

Recommendations for School Policy and Practice

Recommendations for School Policy and Practice		
Recommendation	Description	Considerations/Thoughts from Families
Stock Epinephrine	- Consensus - Recommend that all schools across Canada should have unassigned EAI for anaphylaxis - Funded by provincial government - Helpful for all FAs	- Students with a FA may forget EAI - Students experiencing anaphylaxis may require more than one EAI - Students may experience anaphylaxis for the 1st time at school
Hand Hygiene	-Consensus - Handwashing before & after eating -Helpful for all FAs	- Incorporate into FA awareness education
Sanitizing Surface	- Sanitize all tables after food is served & high touch surfaces to reduce risk of cross-contamination - Helpful for all FAs	- Who does this? Teachers are busy, schools may not have custodial staff - Consider student or parent volunteers - Difficult to tackle all high touch surfaces (doorknobs, bathroom surfaces)
No Food Sharing	- Consensus - Helpful for all FAs	- How is this enforced? - Incorporate into school-wide FA education
School Signage	- Increase nut-free/nut-aware signage in visible areas in school	- junior school, school entrance, classroom doors, where food is served

Maintain Nut-Aware Policies in Schools	- Consensus to keep nut-aware/nut-free policies in place at this time, with emphasis on young school-aged children	- School leadership must set the tone for school-wide adherence - Despite nuts still making their way into the classroom, families believe a nut-free school still reduces risk
Food Allergy Awareness & Education	- Signs & symptoms of anaphylaxis, FA can be life-threatening - How to read food labels - How to use an EAI - Helpful for all FAs	- Target entire school community including parents of other students - Teachers & volunteers need to be aware of who has allergies, where EAIs are stored, when & how to use

Stock Epinephrine

All parents of children or youth with a FA recommended that schools be stocked with unassigned epinephrine for students. Reasons given in support of having unassigned epinephrine at school included: if a child forgot their EAI at home, if a child required an additional dose of epinephrine while waiting for emergency services, or if a child experienced anaphylaxis at school for the first time with no known previous allergy. There was also consensus that this should be provided through government funding. Epinephrine is a life-saving medication for anaphylaxis and schools should have access to this as well as learn and practice how to use it.

Hand Hygiene

Participating families had consensus that promoting handwashing and good hand hygiene was an essential component for FA safety in school. Sandra promoted washing hands as an important safe practice to minimize cross-contamination for all students, sharing:

Hand washing does wonders. Just simple handwashing, wiping your mouth after you eat does wonders for things, like cross-contamination and kids lining up and just kids washing their hands before they go out to play. Like, I think that does wonders for

removing the allergens themselves, just a quick wash and dry of the hands. (P08, Interview 2)

While Sarah acknowledged her son's school required students to wash their hands before eating, she recommended that washing before and after would enhance safety for all students with a FA. She shared:

I don't know if they were washing after they ate, but 100% guarantee they were washing before they eat. And it was the same in Grade 1 and Grade 2 and now in Grade 3. Now, I am sure they wash their hands before they eat, but nobody washes their hands after, which would be a very helpful thing in a classroom with allergies. (P13, Interview 1)

Claire (age 8) also stressed the importance of handwashing for FA safety. She recommended this be implemented at school, "Some people don't wash their hands after they eat. I feel like, it's like, not a strict rule, but you should probably do it" (P16, Interview 1).

Sanitization of Surfaces

Another safety recommendation made by families was to minimize cross-contamination risks in high-touch areas within the school by increasing sanitization protocols. Although all shared the perspective that wiping tables would be helpful, concerns were raised that only wiping tables was insufficient and about who should assume responsibility to do so. Ruby shared her perspective that wiping tables was not sufficient, sharing:

I feel that one is tricky because the school now, they do wipe the counter down, but there is still the grab areas, right? The high touch...and the kids will grab the table to pull themselves in, they touch the microwave, they touch everything, so just the tabletops is limiting. And even when they come to school in the morning, how many kids have peanut butter for breakfast, and it is still on their face or it is still on their hands? (P02, Interview 2)

Lynn further commented on other high touch areas in the school, sharing, “They are children, they go to the bathroom, and they have stuff all over their hands. They touch the door; they touch the chairs” (P06 Interview 2).

There was no consensus on who best would be responsible for this. Claire (age 8) shared that her teacher “wipes the tables after we eat” (P16, Interview 1), while Owen’s (age 10) classmates shared the responsibility for spraying down tables. Lynn shared her perspective:

I am not relying on my students to clean tables for me. And we don’t have a janitorial staff who comes and cleans the tables. As a classroom teacher and a mom with a kid with a FA, I am going to be aware of the fact that kids do not do a good job washing the tables. All classes with allergies should have an adult washing the surfaces. Custodial staff should clean their room. It is not my job [teacher] to wash tables. (P06, Interview 1)

The recommendation to wash surfaces to minimize cross-contamination risks extends beyond table surfaces to include other high touch surfaces and ideally, would be carried out by school custodial staff.

No Food Sharing

All families agreed that a ‘no food sharing’ policy is helpful for contributing to FA safety of all students at school. That said, there was acknowledgement that this policy may be difficult to enforce. All children reported that their schools did not allow food sharing. For older youth, they were uncertain if the school had a policy or it was simply discouraged. Anna (age 15) shared, “Both schools also did have a no food sharing policy, but it is not really enforced (P04, Interview 1). For Jack (age 16) he did not share food for his own safety, not because it was a school policy, “Yeah, that’s something I took upon myself, just so I could be more careful” (P21,

Interview 2). Families did support the recommendation of a no food sharing policy as they acknowledge this would be helpful for all students with different types of FA.

FA Signage

Visible FA signage was another strategy that families recommended as a tool to promote FA safety and awareness within the school environment. Anna (age 15) recommended increased signage, “I would probably say for lower grades, just have more signage and make other kids more aware that allergies, like, do exist, like, put a ‘No Nuts’ sign in the elementary cafeteria” (P04, Interview 1). Jack (age 16) recalled the signage in his elementary school, sharing:

When I was younger, there were posters on the wall of, like, when I was in first grade. And they list the people allergic to certain stuff so that classmates know what to bring and what not to bring. And under my name on the poster it said, like, don’t bring tree nuts, don’t bring fish. (P21, Interview 2)

Jack’s mother also shared, “It’s everywhere on the school, and in the newsletter as a reminder not to send in these foods” (P11, Interview 2). Another mother noted that in the staff bathroom, there was signage to help identify children with FA.

I did notice that in the staff bathroom on the main floor of the school, there was a printed school picture of every child with what their allergies were. I felt great because it is in their face every time they use the washroom. It’s a quick reminder these children need to be extra safe with them. (P13, Interview 2)

To further promote awareness, some parents recommended signage at school entrances and near classroom doors identifying all the allergies present in each classroom.

Maintain Nut-Free/Nut-Aware Policies

Families acknowledged the limitations of nut-free/nut-aware policies in schools yet emphasized that these policies should remain in place as an important aspect of school safety, particularly for younger school-aged students. One mother shared her perspective on the importance of having nut-free policies for school-aged children, “I think especially for the kids that are maybe younger than teenagers they need to have that policy because I don’t think a lot of them are responsible enough” (P19, Interview 2). A youth also shared her perspective about focusing on school-aged children, stating that nut-free policies are “probably more important in the younger grades since the kids in those grades don’t have as good judgement. Like, they may see something they want and probably not understand the consequences especially if they haven’t reacted before” (P04, Interview 1).

Adherence to school policy was an area of concern raised by families. School administration, particularly principals, play a key role in policy enforcement and adherence within the school environment by setting the tone for FA safety and inclusiveness. For example, policies need to be clearly articulated with a consistent approach from all school staff in how FA safety is addressed in the school. A part of policy adherence is raising FA awareness through education to increase knowledge and awareness. Ruby recommended policy would be better adhered to if it came with education offered to the school community, sharing:

So, yes, I do think there needs to be a policy, but it needs to be more strictly enforced. I do think though if there was education to support it [policy] on saying we are a nut aware school, or this is our policy and this is why and going into detail and full-on education on why we need to have this in the classroom or in the school system. I think start there. The more education, the more chance they are going to follow it. (P02, Interview 1)

Recommendations about communicating FA policy is that it should be clear, transparent, consistent, and targets the entire school community. This includes school newsletters and FA signage throughout the school. Principals play a key role in ensuring adherence to FA safety policy by setting expectations for teachers and the broader school community. Families do not expect perfection but believe schools have an obligation to make every effort to promote safety and inclusiveness for their students.

Food Allergy Awareness and Education

Although some families believed that knowledge about FA was more commonplace today, there was acknowledgement that the school community would still benefit from increased FA awareness, safety practices, and management of anaphylaxis. Families did articulate that there was still a lack of understanding from others including some teachers, classmates, and the parents of other classmates. From Sandra's perspective, "A lot of these people who are in charge of these policies have good intentions but maybe just don't know what it's like living out the actualities of it and how they are performing out in practice" (P09, Interview 2). Katie (age 14) recommended that those who work at the school must first be educated so they can promote a climate of inclusiveness and educate others.

So, just for them [school] to know more about allergies and to also make sure they know how to educate people and students on having allergies so then they, the students, can also understand about them more. And also, to make, to know how to make students feel comfortable with allergies and included and different things like that. (P01, Interview 1)

Sandra recommended targeting the following areas for education,

I think some basic boundaries, you know, handwashing, understanding anaphylaxis, understanding how to use the EpiPen. It should be mandatory teacher training for every

single teacher. A lot of teachers just don't understand what anaphylaxis even looks like.

Everybody thinks it's hives, but it's not always hives. (P09, Interview 2)

She also suggested that schools access readily available resources such as Food Allergy Canada online support tools or inviting the school division's public health nurses to provide education for the teachers as part of a professional development day. Another mother, Ruby, offered her recommendations about FA education:

They have to know it is life-threatening. That this should not be taken lightly. It should be, annual training like there is to the staff on first aid. I think that is important. But parents too. I think, I still believe, if you are not in it, then you don't know. So, sending more education, information to parents who aren't in it to help understand why we take this seriously, why it is a big deal, what it means to read a label, will only benefit everyone. (P02, Interview 2)

FA awareness also included ensuring teachers are aware of their students' allergies within the classroom. Anna (age 15), a youth with a peanut and tree nut allergy, recommended that schools:

Know the kids who do have an allergy, because sometimes teachers, I don't think they remember or they often forget allergies exist, so I think it would be helpful to have a list, to let them know who or if kids in their class do have an allergy just in case they do want to bring in food. (P04, Interview 2)

Anna also felt that equipping students with knowledge about FA would help them both at school and in the community, "educating kids about allergies would also be important because they are not always going to be at school. They are going to hang out outside of school too."

Another recommendation for school administration is ensuring that all paid or volunteer personnel involved in a hot lunch program at school or supervising during meal times have training in recognizing the signs and symptoms of anaphylaxis, knowledge about where EAs are stored, and which children have an identified FA. Ruby, mother of a youth with a tree nut allergy and school volunteer, recommended that there should be a list for those with allergies and a corresponding picture for identification. She recommended:

The child's faces on a picture. I think, currently, especially if it is cafeteria type eating and is run by volunteers, there should be a list and a picture of the student. Every year this should be updated. And it should be there in our face, especially for volunteers. (P02 Interview 1)

FA awareness should extend to the parents of students without FA to help reduce food allergens from entering the school. Linda shared her perspective on making a commitment to raising awareness for everyone in the school community, "I think just better awareness, honestly. Like, better education and awareness is what needs to happen" (P17, Interview 2). Sarah echoed this elaborating,

It would be nice if the awareness was sent to all families, so there could be a caution. Maybe, you know, instead of sending the sesame seed bagel to school, they eat it at home for breakfast before they go to class. And they washed their hands. Yeah, awareness would be great. (P13, Interview 1).

This was also recommended by children and youth. Liam (age 11) suggested "telling parents, so that they don't actually send what they are allergic to" (P10, Interview 1). Katie (age 14) further noted, "Just making sure that other students' parents know about kid's allergies too in case they are bringing anything in for birthday or snack or something so everyone can feel included" (P01,

Interview 1). The recommendation to extend FA awareness and education to parents of children without FA is rooted in the recognition that these parents may have limited exposure to FA and may be unaware of the risks associated with sending allergenic foods to school.

Summary

This chapter provides a comprehensive account of the findings of this study, illuminating the lived experiences of children and youth with a life-threatening FA, along with their parents, with Striving for Safety as the central theme woven through each of van Manen's five existentials. The findings highlight the interconnectedness of environments and relationships across home, community, and school, consistent with the EST, where the interaction of microsystems shapes the lived experiences of FA in children, youth, and parents. The chapter also outlined participant informed recommendations for enhancing school safety. Next, the final chapter provides an interpretive discussion about the key findings of the study, situating them within the theoretical foundations and existing literature. It will consider the strengths and limitations of the study, and as well, articulate knowledge dissemination strategies. Finally, recommendations for policy, education and practice, and future recommendations are provided, along with concluding remarks.

Chapter 7

Discussion, Recommendations, and Concluding Remarks

This final chapter begins with an interpretive discussion of the study findings, situating the lived experiences of children, youth, and their parents within existing literature and the theoretical frameworks that informed this research. Drawing on van Manen's hermeneutic phenomenology (2014) and Bronfenbrenner's EST (1977), this chapter explores the meaning of FA experiences and how they may be shaped through relationships, environments, and everyday practices. Attention is given to the study's strengths and limitations. Next, the chapter presents the recommendations for policy, education, future research, and considerations for knowledge translation. The chapter concludes with reflections about the study significance in deepening our understanding of FA to promote safe and inclusive school environments for those with FAs.

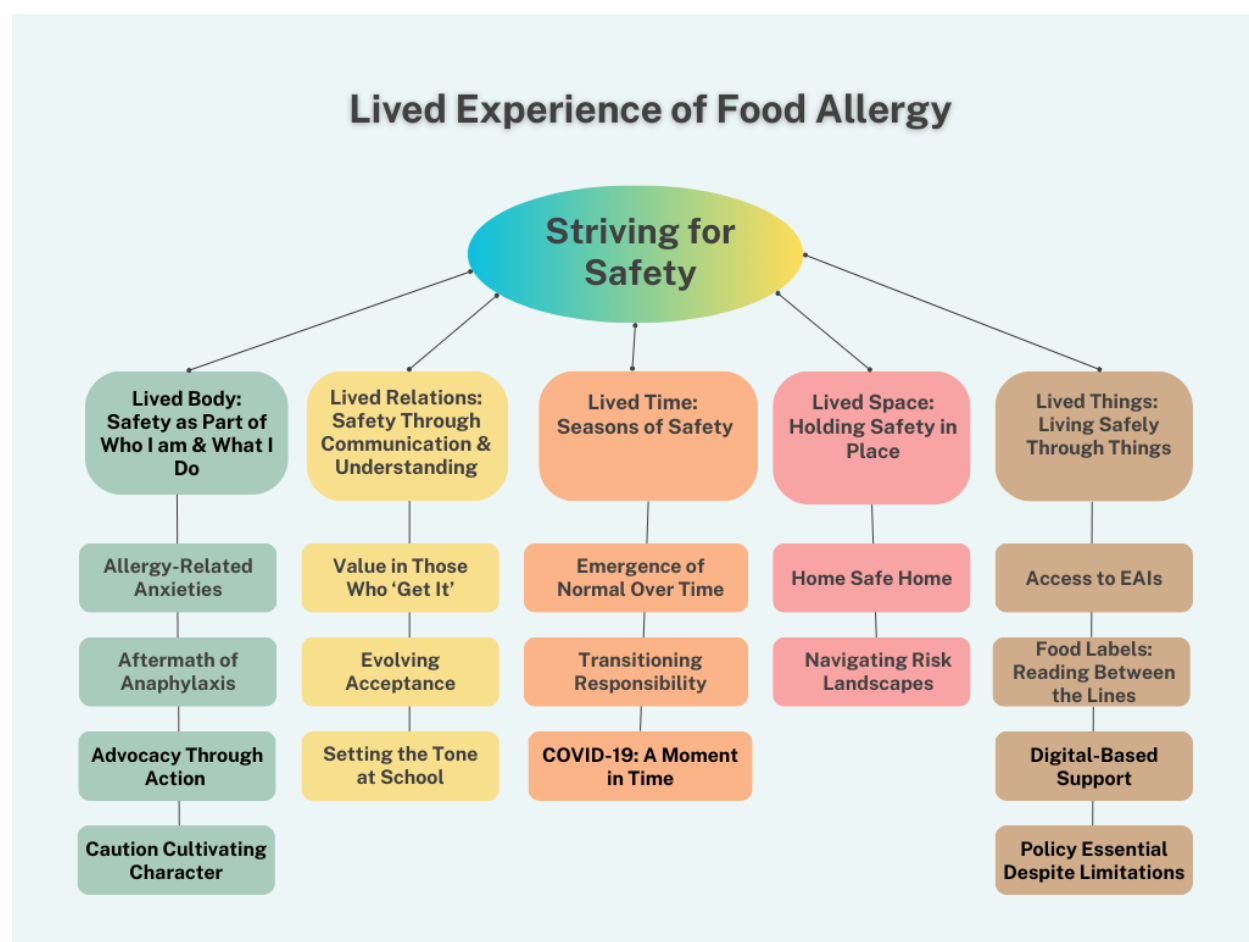
Discussion

The purpose of this research study was to arrive at deeper understanding of the lived experiences of FA within the school environment from the perspectives of children and youth with a FA, and their parents. This purpose was achieved through rich participant accounts that highlighted how FA is experienced in everyday life. Many of the findings are consistent with existing research and provide an additional layer of depth to our current understanding. That said, several novel findings emerged, including the identification of a policy-to-practice gap in lunchtime supervision, variability in families' approaches to precautionary food labels, mothers' advocacy enacted through volunteer roles at school, and the significance of online communities as important sources of education and support for mothers. For this study, a lack of bullying was reported by children and youth, which contrasts with previous research suggesting that FA-related bullying remains common place at school. This study is also the first known to explore

parents' perceptions of the positive character growth they have observed their children develop as a result of managing a FA. Guided by van Manen's five existentials, the meaning of lived experience is interpreted and contextualized within the EST and existing literature. To facilitate the discussion, Figure 17 offers a graphic summary of the themes and subthemes that emerged from this study. Additionally, the recommendations made by children, youth, and parents will be considered in the context of current research practice and guideline recommendations.

Figure 17

Lived Experience of FA



Lived Body: Safety as Part of Who I am and What I Do

The theme for lived body, *Safety as Part of Who I Am and What I Do*, reflects how living safely with FA or caring for a child or youth with a FA becomes integrated as part of oneself and is embodied through everyday practices, relationships, activities, and environments. From an ecological perspective, these embodied experiences are demonstrated through how children and youth position themselves within their microsystems (e.g., school, community) and interact within the mesosystem where food exposure is possible. A school with a nut-free policy is an example of an exosystem in this study that contributes to an environment where students with peanut and tree nut allergies can experience a felt sense of safety and normalcy.

Allergy-Related Anxieties

Allergy-Related Anxieties (ARAs) are negative feelings that can emerge from some of the experiences of living with FA and can shape subsequent interactions and experiences. These feelings may arise from an actual or perceived threat to one's safety or in the case of parents, a threat to their child's safety. In 2021, Westwell-Roper and colleagues conducted a systematic review of 98 studies with its purpose to add clarity to the concept of FA specific anxiety (FAA). These researchers defined FAA as having affective components or emotions (e.g., afraid, terrified, stressed, scared) with cognitive dimensions (e.g., uncertainty about allergen exposure, worry related to FA management, social isolation, life transitions), behavioural components (e.g., social avoidance, limiting child's participation, and intolerance of uncertainty) and physiological dimensions (e.g., physical symptoms or sleep disturbances). Likewise for parents in this study, the affective components or emotions for ARAs were articulated using a variety of different descriptors such as worry, concern, uncertainty, and stress both in interviews and as depicted on ecomaps. The cognitive dimension of ARAs among the parents in this study were

focused on how to provide safe care and prevent exposure to the food allergen. ARAs were also shared in the context of concern about allergen exposure through cross-contamination in uncertain environments and when in the care of others. There were no parent accounts of physiological symptoms or sleep disturbances experienced because of their ARAs, which closely aligns with Westwell-Roper's review in which only two of the 98 studies reported physical or sleep impairments by parents of child with a FA. The findings of this study not only support the conceptualization of FAA in parents by Westwell-Roper but also make an important conceptual contribution by extending FAA to include children and youth living with FA.

Although all parents in this study shared that they experienced ARAs, there was wide variability in frequency, intensity, and duration. While this cannot be quantified, ARAs were seemingly more pronounced in families managing severe and/or multiple allergies, or families that experienced anaphylaxis. Similar experiences of increased worry and fear were reflected in an earlier study (Gillespie et al., 2007) about mothers' experiences of caring for a child with food-induced anaphylaxis, as well as in Polloni and Muraro's (2020) review on anxiety and FA, and in O'Sullivan et al. (2026) research exploring parental roles in FA. In research spanning over two decades, reports of similar ARAs experienced by parents remain despite cultural shifts of increased awareness of FA, implementation of school policy, and calls for expanded educational and psychosocial resources. This may also suggest that ARAs are deeply rooted in a parental need to safeguard their child from harm, anaphylaxis, and death. It further underscores the need for healthcare professionals such as allergists, family doctors, nurses, nurse practitioners, or school counsellors to screen and provide psychosocial supports for parents who may be unable to cope or manage these feelings.

ARAs which varied in frequency, intensity, duration was also described by children and youth in this study. Unlike their parents, they did not use the term anxiety to describe these feelings during interviews or on their ecomaps; rather, they used descriptors such as concern, uncertainty, annoyance, being uncomfortable, or feeling scared. For children and youth, these ARAs were most often about cross-contamination (e.g., classmates not washing their hands after eating), having an allergic reaction at school, uncertainty about safety in unfamiliar environments or with those who may not understand their allergy. The experiences of children and youth in this study align with a recent systematic review of 13 studies from 2009–2004 which highlighted the fear, anxiety, and emotional stress that can occur when living with FA (Nishida et al., 2025). Included in this review was a study involving children and youth (ages 10–14) who similarly described a range of unsettling emotions such as fear, uncertainty and nervousness related to fear of allergen exposure (Martinez et al., 2024). Ciaccio et al.’s findings that FA-specific anxiety among those with multiple FAs varied across individuals and within the same individual (2024), while findings from Kubala et al.’s study (2024) suggest that those with multiple or severe FAs or who had a recent experience with anaphylaxis trended toward worse FA QoL reports. Findings from this study supports both, suggesting that experiences of FA-related anxiety or ARAs were variable among child and youth participants but appeared most pronounced among those with multiple or severe FAs or a history of anaphylaxis.

There are variable reports in the literature about psychosocial issues such as anxiety, depression, and social isolation during adolescence. While the youth in Anderson and colleagues’ study (2021) about FA experience indicated that worry, stress, and discomfort shifted to feelings of increased normalcy, self-acceptance and improved social experiences during adolescence, Polloni and Muraro (2020) cautioned that the transition from childhood to

adolescence was a time where increased anxiety, stress associated with FA management, increased risk of social exclusion and bullying could peak. Quach and John (2018) reported that adolescents are four times more likely to develop psychosocial issues such as depression or anxiety because of their FA. In this study, all five youth participants described increased comfort rather than heightened psychosocial concerns compared with the ARAs they recalled experiencing when they were younger. Notably, the youth with a history of anaphylaxis reported that his allergy was improving with age, while the absence of recent anaphylactic experiences among the other youth may also have contributed to ARAs being perceived as less bothersome. Further, children and youth denied being socially excluded from friends, rather sharing that their close friend groups were respectful, understanding, and supportive of their FA. This echoes the findings from Johnston's study (2024) where youth with a FA shared that the more they felt they could trust their friends about their FA, the closer the relationship and feelings of security.

Overall, the results of this study are consistent with existing literature that suggest that living with FA is associated with psychological burden that varies for each person and within each person's experience. Further, this study's subtheme, Allergy-Related Anxieties, aligns with Polloni and Muraro (2020) description of FA anxiety and Westwell-Roper's (2021) conceptual definition of food allergy-related anxiety as distinct from generalized anxiety in two ways. First, feelings of worry, stress, and fear were centered on the safety risks inherent to those living with or caring for someone with FA. Second, there was absence of reported physiological symptoms that is associated with generalized anxiety among children, youth, and parents in this study. Taken together, these findings suggest that Allergy-Related Anxieties represents a distinct concept that is different from generalized anxiety.

Aftermath of Anaphylaxis

The subtheme, *Aftermath of Anaphylaxis*, captures the experiences of children, youth, and parents who described heightened anxiety and vigilance after an anaphylactic reaction. Children and youth also reflected on the intense bodily sensations of their allergic reaction, which remained with them as a reminder of risk. In addition to experiencing physical symptoms, children and youth reflected on the actions that followed including epinephrine injections, transport by ambulance, and treatment in hospital which all shaped how they subsequently move through and interact with the world. For parents, although anaphylaxis was not a bodily experience in the same way, it was lived through observing their child in immediate danger and having to act under urgent, life-threatening conditions. For children, youth, and parents, these experiences left a lasting emotional imprint that was marked by heightened feelings of anxiety and fear and a recommitment to hypervigilance in FA management. The subtheme, *Aftermath of Anaphylaxis*, aligns with the research by Johnson (2024) where youth described the bodily sensations during anaphylaxis and the lasting effects of anaphylaxis on the body, mind, and social interactions. Parents in this study also described their child's anaphylactic reaction as traumatic for the family and left them with heightening feelings of anxiety, vigilance, and guilt which were comparable to parent accounts described by Gallagher et al. (2012) and Chooniedass et al. (2018). A few parents described how, despite anaphylactic reactions being frightening experiences, they served as a learning opportunity for future reactions by preparing them to recognize signs and symptoms of anaphylaxis and with the hope that they will respond more quickly. Similarly, this was described by Chooniedass and colleagues (2018) as lessons learned in their qualitative inquiry exploring parent experiences with epinephrine use for their child's anaphylactic reaction to a FA.

Advocacy in Action

Advocacy Through Action, was experienced as lived body, and captures how parents are compelled to be active agents in creating safe relationships and environments for the purpose of maintaining safety in their child's lifeworld. Although Woodgate (2015) discussed the roles of a good parent and advocate in the context of parenting a child with complex care needs, these roles have not yet been specifically highlighted by parents of children with a FA. While all parents naturally act as advocates for their children, this role is often felt more intensely by parents of children with special needs, as Woodgate emphasized. Similarly, parents of a child with a FA described a need to advocate more intensely, driven by the recognition that any lapse could result in life-threatening consequences for their child, leading them to assume multiple advocacy roles. At its core, advocacy requires active and ongoing communication to construct or maintain safe environments. From an ecological perspective, parents interacted with the child's microsystems of school, teachers, peers, and other parents. Parents were engaged with the exosystem such as industry (e.g., calling companies about food allergens) and school policy (e.g., advocating for better adherence, choice of school).

Before being able to advocate for their child, parents described first educating themselves and then educating others, including grandparents, teachers, and friends, about the seriousness of FA, safe management practices, recognizing allergic reactions, and how to administer an EAI. This type of education often required ongoing reinforcement to ensure understanding. At the same time, parents were also keenly aware of the relational risks with such communication, describing a balancing act in ensuring their child's safety with concerns about appearing overly assertive or a burdensome to others. Advocacy also involved proactively seeking food safety information including parent communication ahead of birthdays, contacting restaurants to inquire

about their allergen menus and policies, and seeking clarification from food manufacturers regarding precautionary allergen labels. These examples of advocacy align with the concept of communication work expressed by Bute et al. (2022). In Bute and colleagues' study (2022), parents described the communication required for FA safety on behalf of their child including giving blunt instructions, repeating messaging, and requesting food information all while being conscious of trying to balance the relational impacts.

Another notable finding, one that to my knowledge has not been previously reported in the literature, was the extent to which many mothers assumed active volunteer roles within their child's school because of their child's FA. Volunteering at school represented a strategic positioning to advocate for FA safety by being present to monitor, influence, and respond to concerns within the school environment. Some mothers described joining parent council to get a better understanding in how FA was treated in the school and to have an opportunity to promote FA awareness, ensure policy adherence, and safe practices. Volunteering in other roles such as lunch monitor, hot-lunch volunteer, or for school bake sales allowed them further opportunities to observe, participate in, and influence how food was managed in the school. Enacting advocacy through assuming volunteer roles reflected a deeply rooted commitment and responsibility toward their child's safety. Further, being able to advocate through their volunteer presence at school appeared to provide mothers with a sense of reassurance regarding safety and minimized feelings of uncertainty about FA practices in settings in which they had minimal control.

For children and youth, Advocacy Through Action, was reflected as self-advocacy and demonstrated through their actions in learning to communicate about their FA and taking precautionary measures such as reading food labels and remembering to always have access to their EAI. These self-management strategies outlined in this study were oriented toward

maintaining safety in avoiding their FA and being prepared if accidental exposure occurred were similar to findings articulated by O’Sullivan et al. (2025) and Nishida et al. (2025). For children living with a FA, these practices were not only a routine safety measure but became in internalized as part of their self.

Caution Cultivating Character

Caution Cultivating Character illustrates how the lived experience of FA shapes the self and can foster the development of positive character attributes among children and youth. Parents described how living with FA contributed to their child’s positive character growth, identifying qualities such as responsibility, caution, resilience, empathy, and possessing strong will power or delayed gratification. Pride in their child was evident in their choice of words and some parents also demonstrated this with emotion (e.g., getting teary-eyed). Not only were these attributes reflected on with pride, but they also helped foster parents’ trust that their child would navigate their world with safety and caution in mind. To my knowledge, parental descriptions of character growth in children or youth, in particular delayed gratification, have received little attention in published research to date.

Although children did not explicitly talk about their own character growth, some youth described themselves as developing increased comfort and confidence in speaking to adults because of living with FA. Responsibility was demonstrated through their daily self-management practices. These findings echoed Anderson et al.’s study, which interviewed young adults (ages 18-21) who reflected on their experiences of FA and described positive aspects such as learning responsibility, having empathy for others, and learning to be their own advocate (2021). Similarly, a qualitative study by Fenton et al. (2013), adolescents described themselves as taking on more responsibility in self-management of their food allergy. This was also reflected

in Warren et al.'s (2017) study of FA risk taking practices, in which adolescents expressed their belief that FA made them more responsible and a better advocate for themselves and others. It is important to acknowledge that parents in this study did not discuss their own character development in caring for a child with FA. It is unclear if this was because they did not see character growth in themselves, were focused on their children's growth, or if it was simply a matter of not being asked directly about themselves in the interview.

Lived Relations: Safety Through Communication and Understanding

The theme, *Safety Through Communication and Understanding*, was deeply relational. Safety was felt most strongly with interactions with family, friends, community members, and teachers who conveyed trustworthiness through attentive listening, communicating their knowledge about managing FA, and their actions which provided the children, youth, and parents with a sense that their FA was understood and taken seriously. In turn, these relational qualities promote feelings of connection and inclusivity within their environments. Conversely, a lack of empathy or awareness about FA can contribute to feelings of uncertainty, frustration, and concern for safety. From an ecological perspective, relational experiences reflect interactions within and across microsystems and the mesosystem including the home and school, as well as connections between parents and teachers and/or principals.

Value in those who 'Get it'

The findings of this study underscore that close, trusted relationships shape the lived experience of parents, children and youth with a FA in fostering a sense of safety and comfort and were highly valued. Conversely, when participants observed a demonstrated lack of FA awareness in others, it contributed to feelings of stress and uncertainty about the ability to maintain safety. Many parents described having a close circle of friends and family that

understand their child's FA and the accommodations required for safety. Families spent considerable effort fostering FA safety in relationships which was also articulated by Hurst et al. (2021). In this study, friends and family demonstrated this awareness and commitment to safety through actions such as taking a FA safety course, learning how to use an EpiPen, taking pictures of food labels or contacting them in advance to discuss safe foods to serve at a social event. Parents expressed deep gratitude and appreciation for these actions, instilled a sense of trust, and led to increased feelings of comfort and safety when socializing. Conversely, when actions demonstrated a lack of awareness such as serving or not putting away food allergens despite being told contributed to feelings of frustration and heightened worry about safety for that time and forced some parents to have to make difficult decisions on whether these relationships were worth continuing. Hörold and colleagues (2024) emphasized the importance of informal support networks, such as close friends and extended family, noting that a lack of support can be burdensome; this was echoed in this current study and in Abrams et al.'s (2020) research, where families describe feeling overwhelmed and alone when support from extended family or their inner social circle was perceived to be lacking.

Supportive and understanding friends were described as important to a child or youth feeling comfortable and safe about their FA in environments outside the home. Good friends that understood FA was a buffer to feeling different or isolated because of FA (Anderson et al., 2021; Elliot et al., 2015). Similar to the findings of previous research, children and youth in this study emphasized that their close friends understood and helped support their FA accommodations. This fostered a sense of comfort, trust, and contributed to feelings of normalcy within their school environment and when out with peers. Children and youth in this study shared that while most people were respectful of their FA, a lack of understanding by teachers, classmates, and

other parents was still felt at times at school which was a source of frustration and contributed feelings of being uncomfortable in their environments. A lack of understanding from classmates has continued to be reported as highlighted in Nishida's systematic review (2025), while a school-wide lack of awareness was a barrier to feeling understood and accepted at school (Newman et al., 2022).

Evolving Acceptance

Another significant finding that contrasts with previous research, is that bullying was not a part of the lived experience for the children and youth in this study. Previous research regarding the prevalence of FA-related bullying in children and youth has been reported to range from 20–34% (Brown et al., 2021; Cooke et al., 2021; Liberman et al., 2010; Rocheleau & Rocheleau, 2020; Shemesh et al., 2013; Torabi et al., 2016) to as high as 42-60% (Fong et al., 2018; Muraro et al., 2014; Shemesh et al., 2012). Further, findings from a more recent review, suggest rates of FA-related bullying were 20–32% among children and youth (Golding et al., 2022), while Valero-Moreno (2024) report over 40% of children with FA are bullied, with over half experiencing bullying of a physical nature. In this study, children and youth denied being verbally or physically bullied because of their FA. Only when questioned did some participants provide examples of some instances of teasing by their friends when they were younger at school but emphasized it was never persistent or felt to be mean-spirited. Moreover, they felt that in general, most people were always respectful of their FA, despite instances of a lack of awareness. Some youth described that people today are more accepting of FA and related accommodations compared to earlier experiences when they were younger. From an ecological perspective, the lack of reported bullying may reflect a broader cultural shift within the macrosystem towards increased awareness, mindfulness, and respect for individual

differences, including FA, in Canada. Given the small sample size of this study and the aforementioned research suggesting that FA-related bullying is still commonplace in schools, more research is necessary to determine if this was an anomaly, reflective of the parents' high education level and socioeconomic status, or a change in cultural norms and attitudes.

While bullying related to their FA was not a part of children's and youths' experiences at school, some participants did indicate that they were occasionally left out or excluded in the classroom setting because of their FA. This finding aligns closely with previous reports of feeling left out or excluded at school because of their allergy (Dean et al., 2016; Johnson, 2024; Martinez et al., 2024; Nishida et al., 2025). While all teachers appeared to have a system in place to have safe treats for school celebrations (allergen free snacks purchased by teacher or parents), some children and youth still felt left out or different because they were unable to have the same treat as their peers. Children and youth also shared instances in which they were excluded from class activities involving food due to teacher oversights (e.g., science experiments involving food). In these situations, the connection between the activity and FA safety was not always anticipated by school staff resulting in the child or youth being unable to participate. When this occurred, safety was managed through segregation with students being asked to work independently in the hallway or another classroom. These examples were not commonplace and were addressed promptly between teacher and parent; however, they serve as an important reminder of the unforeseen risks associated with FA and the unintended consequences (i.e., segregation and exclusion of student with FA) that may arise in the school environment.

Setting the Tone at School

This study's findings underscore the pivotal role of school administrators in *Setting the Tone at School* and the need to provide strong leadership for FA safety within the school

environment. Communication is a key element of this leadership and is essential in establishing trust that FA safety is a priority. Initial meetings between parents and principals where policies were clearly articulated, safety concerns were listened to and addressed empathetically went a long way in easing anxieties, instilling confidence, and reassurance for parents. School-wide communication such as newsletters to families, consistent messaging, and school-wide signage further signaled that FA was taken seriously. Parents also valued ongoing communication about FA with their child's teacher throughout the year, as it fostered a sense of trust and reassurance that FA were top of mind. This finding supported previous research that identified poor communication as a barrier to a smooth transition to school and parents recommend establishing open communication between schools and parents (Sanagavarapu, 2018).

When school leadership failed to set the right tone, individual teachers were often left to fill this gap by providing support and communication about FA in their classroom for families with FA. This contributed to variable experiences of support and, at times, inconsistent adherence to established FA policies. Further, when there was a lack of a school-wide approach, it undermined trust and fostered feelings of worry and uncertainty about their child's safety. This finding of parental mistrust was also expressed in a study by Dupuis et al. (2020) where feelings of mistrust were intensified by miscommunication between parents and school and an inconsistency in school's adherence to their own policies. The findings of this study support the work of Lövquist et al (2024) who captured four primary needs from parents: well-implemented routines, demonstrated allergy competence amongst school staff, that their child is treated equally or inclusively, and to feel trust. For parents, trust required feeling understood, being taken seriously, and having confidence in the school's ability to care for their child safely. In this study, this began with school leadership and had a ripple effect throughout the school.

Lived Time: Seasons of Safety

The theme, *Seasons of Safety*, is reflective of the evolving, temporal experience of living with FA marked by shifting perceptions of risk, adaptation, and changing responsibilities over time and developmental stages. Current experiences are inevitably shaped by past experiences of FA and cumulatively shape perceptions navigating future events. From an ecological perspective, the chronosystem is reflected both in the transitioning responsibility from parent to child and as well, in the COVID-19 pandemic and its impact of FA safety practices at school.

Emergence of Normal Over Time

All families shared that there was an *Emergence of Normal Over Time*. That is, there was an acceptance of FA and an adaptation to the routine practices in the home required for safety that came to feel normal over time. This finding was identified in Golding and colleagues' (2022) review of the burden of allergy on children and teens in that over time, children adapted to living with FA and the burden of food allergy was minimal. Fenton et al. (2010; 2013) also reported that adolescents described living with FA as redefining their life as normal. Similarly, Dean et al. (2016) indicated that some youth normalized their experiences with FA, accepted their diagnosis, and adapted their lives accordingly. It is important to note that although families in this study adapted to living with FA as normal living over time, this did not preclude instances of heightened stress or allergy-related anxieties. For some, living with allergy-related anxieties became part of what was experienced as normal.

Transitioning Responsibility

Transitioning responsibility of FA management from parent to child emerged as a noteworthy aspect of family experiences. Parents were cognizant of the importance of being able to self-manage FA and were intentional in the preparation of teaching their child to assume

greater responsibility gradually over time. Likewise, children and youth expressed assuming more responsibility over their FA as part of their experience in living with a FA. Existing research has also highlighted parents' acknowledgement that their children need to learn to self-manage their allergy despite risks associated with adolescence including increased freedom and a susceptibility to peer pressure (Gallagher et al., 2012). From a young age, parents intentionally supported the development of self-advocacy by empowering their child to communicate about their FA, rather than speaking on their behalf.

Although parents in this study emphasized the importance of transitioning responsibility of FA management from parent to child or youth, none discussed the added risks associated with adolescence that other parents have articulated in previous research. For example, parents in a study by O'Sullivan et al. (2026) expressed concern about the hidden dangers of decreased inhibitions associated with drinking alcohol or cross-contamination risks from kissing. While other research (Moen et al., 2019) pointed to parents having difficulty learning to let go or feeling comfortable handing over control to their child, this sentiment was not commonly expressed amongst parents in this study. Instead, many parents described actively educating and preparing their child to gradually assume more responsibility in their own FA management such as speaking up for themselves at restaurants, reading food labels, and remembering to carry their EpiPen. Further, parents articulated a felt sense of pride in observing their child competently manage their FA at school or while spending time with friends. It is unclear why some of the risks associated with adolescence such as alcohol use or romantic relationships did not emerge from the youth or parents. Parents may have been unaware of these dangers or did not think this was a relevant or comfortable topic to share. For youth, it may have been a non-issue, or these risks may not have been disclosed as parents were often nearby for interviews.

Previous research by Newman et al. (2022) and O’Sullivan et al. (2025) have indicated that adolescents can experience difficulties managing their own FA. In these research studies, adolescents voiced fears about having an allergic reaction, having knowledge gaps about their FA, or were somewhat dismissive of high-risk behaviours associated with anaphylaxis.

O’Sullivan et al. described the transition to self-management as an ongoing process and Fenton et al. (2010, 2013) reported that as adolescents gained more confidence in dealing with their allergy, they took on more responsibility for self-management, including making decisions about allergen safety. New to this study, all children and youth, articulated a growing confidence and comfort in managing their own FA. Actions such as remembering their EpiPens, reading food labels, speaking up for themselves, and erring on the side of caution by avoiding unfamiliar or uncertain foods started in early childhood and continued to develop.

COVID-19: A Moment in Time

When asked about how the COVID-19 pandemic impacted the experiences of FA in school, parents, children, and youth did not feel that it made a significant impact on their lives. Parents did acknowledge that when students ate in smaller cohorts, it did minimize the potential for cross-contamination. They also noted that the increased handwashing and sanitization protocols implemented during the pandemic would also contribute to increased safety for students with FA at school. Although this provides a limited perspective from families with FA at school during the pandemic, it does align with the qualitative study by Santos (2023) who sought teacher perceptions on how the COVID-19 pandemic directly impacted FA management at school; determined that enhanced cleaning protocols, physical distancing, and eating in smaller class cohorts with teacher supervision during the pandemic was beneficial for FA management at school.

Lived Space: Holding Safety in Place

Within lived space, certain environments were experienced as places of relative safety and others such as schools and other community venues were perceived as risk landscapes that required thoughtful preparation and navigation to ensure FA safety. From an ecological perspective, lived spaces are regarded as microsystems when the child or youth is directly interacting with the space. Mesosystems are evident when the parents of a child or youth interacted with the school, with other parents at playdates, or when speaking to restaurant staff about their child's FA. Examples of an exosystem in lived spaces include provincial legislation requiring FA policies at school or restaurants having food allergen guides published on their websites or made available when dining out.

Home Safe Home

In this study, the home was not just a physical location, but a lived space which provided the family with a sense of comfort, safety, and a sense of freedom. According to van Manen (2014), home represents a very special place in which speaks to one's fundamental essence, "home is where we can be what we are" (p.102). This understanding was particularly resonant with this study's findings. For instance, children and youth described home as a place where they could temporarily forget about their food allergy and simply "be." Parents in this study intentionally constructed their home as a safe zone, where the prevention of allergen exposure was supported by established routines and safety practices. These efforts allowed the family to temporarily suspend their allergy-related anxieties and vigilance allowing for feelings of belonging, normalcy, safety, and comfort. The conceptualization of the home as a sanctuary that promotes safety and comfort is not novel and supports existing research (Gallagher et al., 2012; Golding et al., 2022; Johnson, 2024; Moen et al., 2019; Stjerna, 2015). Consistent with

Newman et al. (2022), children and youths' feelings of safety and the ability to relax at home were, in part, related to a parental presence. Similarly, the importance of parental presence in the home was also expressed by study participants. Feeling safe was deeply intertwined with close and trusted relationships with parents and siblings, highlighting that safety at home was experienced not only through physical protections, but through relational connection and emotional belonging.

Navigating Risk Landscapes

While the home symbolized safety, environments outside the home where safety was not assured were associated with a perceived risk of an allergic reaction. Navigating risk landscapes such as school, restaurants, or friends' homes symbolized an uncertain lifeworld that required active vigilance and careful navigation. Unfamiliar environments contributed to feelings of uncertainty and fear about safety necessitating parents, children, and youth to actively prevent and manage risk through communication and preparation (e.g., EpiPens, bringing safe snacks). Despite various descriptors of risk landscapes, this was a common experience for families managing a FA in the literature (Golding et al., 2022; Lövquist et al., 2024; Nishida et al., 2025; Valero-Moreno, 2024).

Lived Things: Living Safely Through Things

Lived things represented material items and technologies that extended beyond just physical protection for children and youth with a FA, but rather symbolized safety, preparedness, and reassurance when navigating certain activities, environments, and relationships. In this study, access to EAIs, understanding food labels, leaning on digital supports, and school policy were things that when understood and consistently upheld promoted feelings of safety amongst families affected by FA. From an ecological perspective, these lived things functioned as tools

that moved across systems. For instance, FA policies originating in the exosystem are encountered and relied upon within the child or youths' microsystem of school. Similarly, ambiguous precautionary FA labels are shaped by industry and legislation were read, interpreted, and acted on by families with a FA.

Access to EAI

Across parents, children, and youth in this study, Access to EAI was understood an essential component in living safely with FA. As a lived thing, an EAI's primary function is to deliver epinephrine, a life-saving medication, in the event of anaphylaxis. Having an EAI when out in the world for someone with FA symbolizes preparedness, protection, and an offering of reassurance when navigating the uncertainties in the lifeworld. As such, it is both a material object and a symbolic anchor of safety, reflecting the need to be ready for the unexpected and relied upon for peace of mind. Likewise, in a study by Johnson (2024), young people described having access to an EAI as insurance or a way to manage uncertainty and increase feelings of safety.

Parents, children, and youth with a FA in this study all stressed the importance of having access to their EpiPen when they were outside the home, particularly at school. However, there was wide variability in the number of EpiPens required by the school and where EpiPens were stored while at school. Again, this is reflective of other findings in previous research (Quill et al., 2025; Wasserman et al., 2021) and highlights the need that despite ongoing recommendations, a standardized approach for epinephrine across Canada is still needed.

Food Labels: Reading Between the Lines

For families living with a FA, food labels are material items that guide decisions about safety and risk. The act of reading a label extends beyond simply scanning ingredients; rather, it

becomes an interpretive exercise in risk assessment. Labels about food allergens on products can provide a sense of security and reassurance for families that the food they are purchasing and consuming is safe. However, with the ambiguity of precautionary allergen labels (PAL) such as “may contain” or “processed in a facility”, it forces those impacted by FA to “read between the lines” and make a judgement call about safety based on previous knowledge and experience placing unnecessary burden and stress. Differences in family approaches were shaped not by a lack of vigilance, but rather, uncertainty about Canadian regulations about the level of risk associated with PAL. Although not widely reported in previous research, this finding aligns with the previous research where youth (ages 13-19) shared that they did eat some foods with “may contain” labels as foods with these labels were difficult to avoid due to their prevalence. This was not being dismissive of risk; rather, it was their belief based on their experience that manufacturers used PAL only to avoid litigation (Gallager et al., 2012). In a study on parent perceived policy needs, parents expressed frustration with one mother stating, “I really want to crack this nut of may contain! Does it or doesn’t it?” (Abrams et al., 2020, p.3). Parents in this study recommended further clarity and a standardized approach for PAL from Canadian legislators).

Digital-Based Supports

Another novel finding that emerged from this study was the importance of online FA groups as a valuable resource for mothers. Several mothers described online FA communities, particularly Facebook groups, as meaningful sources of psychosocial support and practical education. For these mothers, Facebook groups functioned as relational spaces where parents connected with others who shared similar experiences. Seeking support within these communities contributed to feelings of connection and validation grounded in the shared

responsibility of caring for a child with a life-threatening condition. In addition to emotional support, these groups served an important educational function, providing spaces where common questions were discussed and FA resources were exchanged between members. Although the use of virtual networks was briefly acknowledged by Hörold et al. (2024), this study offers further insights into how digital supports can be meaningful and beneficial for families impacted by a FA and in particular, mothers. Although not specific to the school environment, mothers who have access to support and information may feel more confident to engage with their child's school to support FA safety.

Policy Essential Despite Limitations

School-based FA policy in Canada is fundamental to creating a safe and inclusive school environment. These findings are significant as they reflect a contemporary perspective on FA policies in schools from the voices of parents, children, and youth. There was a strong assertion by the parents in this study that FA policies in schools were essential, despite their limitations. Parents, children, and youth placed particular emphasis on having policies (e.g., nut-free or nut-aware) established for younger school-aged children. There was acknowledgement that policing nut-free policies in middle and high schools is challenging, in large part due to the fluid nature of movement of older students in and out of the school throughout the school day. Again, all participants felt that food bans should remain in place for younger school-age children because from their view, they still rely on caregivers (e.g., parents, teachers) for FA safety, may lack knowledge, judgement or maturity to make independent decisions about FA safety, and were still learning to manage their own FA. According to Sanagavarapu (2017), a child's understanding and ability to take responsibility for their FA is developmentally based and young children may not be ready to assume full responsibility of their FA. The results of her pilot study reflected the

importance of children learning to let others know about their FA, not sharing food or accepting food from others, and letting an adult know if they feel unwell.

Among parents who had the option of school choice, a school's policies and approach to FA was a determining factor for which school their child attended. One parent interviewed four principals and opted to choose a school that she felt was committed to FA safety despite it being the farthest from home. A youth stated her parents chose a private school that had a nut-free policy and did not segregate students with FA during mealtimes. Another mother shared that choosing a small private school with strong FA policy provided reassurance of a commitment to safety and that smaller classes would translate into more supervision and care.

Variability in school policy and its adherence to school policy remains an issue. Dupuis et al. (2020) highlighted variability in school food allergy policies and inconsistent adherence to them, a finding echoed by mothers in Sanagavarapu's (2018) study who reported concerns with policy adherence and by parents and children in Vollmer et al.'s (2022) study who expressed frustration with inconsistent policy enforcement. This study provides a Canadian perspective from parents, children, and youth all reporting that despite FA in place, there was a lack of enforcement by school staff and adherence by students at school.

While schools often had food allergy policies in place, participants identified a significant policy-to-practice gap related to inadequate food allergy training for individuals responsible for supervising and serving students during mealtimes. Because mealtime supervision may be provided by paid staff, parent volunteers, or older students, participants emphasized the need for consistent training in food allergy awareness, anaphylaxis recognition, epinephrine access, and emergency response. It has been noted in the literature that it is recommended that education and training should be provided to teachers about FA safety and management (Cathcart et al.,

2020; Santos et al., 2023); however, these recommendations do not clearly extend to parent and student volunteers or paid support staff. Although Sanagavarapu (2020) reported that Australian parents recommended an increase in supervision of young children on playgrounds and during mealtimes, it does not address their FA training needs. This study extends these recommendations offering a more detailed, Canadian perspective. Children and youth articulated wide variability in lunch supervision across schools ranging from teachers eating in the classroom, parent volunteers supervising multiple classrooms, to older students being responsible for the supervision of younger students. Some of the parents who volunteered in their child's school shared that they were given no training about FA. Unless parents had personal experience with FA they would not have been educated about how to recognize an allergic reaction, where EpiPens were stored in the school, or given information about which students were at risk for anaphylaxis. Parents also expressed similar concerns about paid or parent volunteers serving food to students at school. They noted there was no FA signage around areas where students were eating and training about FA was also not provided. All strongly recommended that FA education should be mandatory for anyone serving or supervising students during mealtimes at school. In the US, a new federal law, *Protecting Children with Food Allergies*, requires all food service personnel to receive annual food allergy training (Mondello, 2026). Although there are no federal laws in Canada of this nature, providing this type of training of would help to improve FA safe practices at school.

An ongoing narrative in FA research that recommends against food bans in schools is that it may create a false sense of security which could result in less surveillance or reduced vigilance by school staff, students, and families (Bartnikas et al., 2017; Cathcart et al., 2023; Elliott et al., 2015; Huddleston et al., 2020; Vale et al., 2015; Wasserman et al., 2021). The findings of this

study do not fit this narrative, nor was it reflective of participant felt experiences. Children and youth with a FA, and their parents had a realistic awareness that schools with nut-free or nut-aware policies were not 100% effective, and all acknowledged that nuts were noted in environments deemed to be nut-free. Yet, despite this awareness, participants articulated that in establishing these policies, there was still an overall reduced risk of exposure, particularly through a decreased risk of exposure through cross-contamination. An older Canadian study by Banerjee et al. (2007) compared lunches in classes with peanut-free guidelines to those without and lunches from schools that had peanut-free guidelines was found to be substantially less risk. Although this study is dated, it supports that having policies in place may not completely remove nuts but can contribute to a reduced risk of allergen exposure. For one younger child with a nut allergy whose school enforced their food allergen policy quite strictly, shared that she felt normal and did not really worry at school because there were no nuts allowed. That said, this child still adhered to no food sharing, washed her hands before and after eating. Overall, these policies contributed to feelings of comfort, inclusiveness, and safety within the school environment. For parents, these policies offered a sense of reassurance of the school's commitment to safety and policies were something they could fall back on should any concerns arise.

Overarching Theme: Striving for Safety

Taken together, the five existentials of the lifeworld highlight that the core essence of the lived experience of FA is oriented toward *Striving for Safety*. Across lived body, relation, time, space, and things, safety is not experienced as a static condition, rather an ongoing way of being in the world for children and youth with a FA, and their parents. Striving for safety reflects more than the presence or absence of protection against FA; rather, it shapes how individuals inhabit their bodies, engage with others, anticipate future experiences and rely on material supports

while living with or caring for someone with a potentially life-threatening condition. In this way, striving for safety is also formative. For children and youth with FA, it can contribute to positive self-growth, fostering responsibility, resilience, and advocacy. Although most parents assume the role of an advocate and protector for their child, living with FA amplifies these responsibilities where children and parents' actions and decisions may carry life-preserving significance.

Moreover, Striving for Safety is not only about avoiding harm (e.g., allergen exposure), but also, an orientation towards seeking inclusion, a sense of normalcy, and a sense of comfort and reassurance while living with risk and uncertainty.

Striving for Safety was spatially situated within the school environment and was enacted through relationships and material support. School administrative staff and teachers contributed to a felt sense of safety for children and youth with a FA and their parents through ongoing communication and the implementation of school policies such as nut-aware or nut-free policies, emergency action plans, and access to epinephrine. Setting the tone for FA safety in school included having knowledge about FA management, enforcing policies, and open communication with families to create a sense of safety. Participants reflected on current policies and provided their insights and recommendations to create an optimal school environment for those with FA and will be discussed in relation to current expert recommendations will be discussed in relation to current expert recommendations.

School Policy and Practice Recommendations

Children, youth, and their parents provided some valuable insights recommendations for school policy. Key areas will be highlighted within the context of existing research and guidelines.

Stock Epinephrine

In this study, youth and parents all agreed that schools should have unassigned epinephrine at schools for various reasons. The reasons cited include: a child forgetting their EpiPen, a child having an allergic reaction requiring a second dose, or a child with no previous history of allergy experiencing anaphylaxis for the first time at school. This is in alignment with the practice guidelines for the management of allergic reactions in school which recommend that stock, or unassigned epinephrine, should be available in schools instead of requiring all students to store their own EAI at school (Waserman et al., 2021). Parents in this study also expressed that EpiPens should be fully funded by the government for families and schools and availability to EAI in the school and community should be similar for automated external defibrillators (AEDs) or Narcan (a drug to treat an overdose). These recommendations were similar to parent recommendations about policy in a study conducted by Abrams et al. (2020) in that parents believed stock epinephrine follow the same national approach to AEDs. Like recommendations from the United States (Food Allergy Management in Schools [FAMs]; Russel et al., 2023), Food Allergy Canada (n.d.) also recommends nation-wide availability of unassigned epinephrine. There is consensus from parent recommendations, clinical guidelines, and national food allergy groups that unassigned stock epinephrine should be available in all Canadian schools, but to date, this has yet to be implemented despite ongoing support.

Increased Handwashing, Sanitization of Tables, and No Food Sharing

Children, youth, and parents recommended that handwashing before and after meals, wiping down tables, and no food sharing would collectively help to reduce the risk of cross-contamination for students with all types of FAs. This also aligns with the current practice guidelines (FAMS, 2024; Waserman et al., 2021); however, participants in this study did offer

practical insights that merit consideration. In general, it was believed that washing hands before and after meals would be able to be established as standard practice in younger school-aged children but would prove more difficult to enforce in middle and high school years with less teacher oversight and greater student movement across environments. Further, it was noted that during COVID-19, mandatory handwashing school-wide led to long line ups at sinks reducing student lunch time to eat. While one youth suggested hand sanitizer to combat this issue, Greenhawt et al. (2020) reported that hand sanitizer is not effective in removing all food allergen proteins; therefore, cannot safely be recommended as an alternative to hand washing with soap.

Washing tables after meals or at the end of the day was noted as current practice by some children in this study. Sanitizing tables after eating was a recommendation provided by Greenhawt et al. (2020) and FAMS (2024) to reduce cross contamination for students with all types of FA. While participants thought this was a good idea in principle, several practical concerns were identified. First, there was uncertainty regarding who would bear the responsibility for the sanitization of tables. A parent of a child with a FA who was also a teacher, believed it was not within her scope as an educator to be regularly washing down tables. At the same time, there was concern that there may not be adequate custodial staff to accommodate this change in practice. Other parents noted that even if the tables were sanitized, the risks of cross-contamination from other high touch areas such as chairs, doorknobs, and the school playground would remain. Cross-contamination as a risk to safety was also identified by Sanagavarapu (2020) and Vollmer et al. (2022).

A no food sharing policy was also recommended for all students to minimize risk for students with different types of FA. No food sharing policies are already in place in many of the participant schools and is supported by recommendations from Food Allergy Canada (n.d).

Adherence to this policy was noted in this study as a current issue for students' school-wide; however, the children and youth with FA in this study asserted that they adhered to this policy because they understood the danger of food-sharing and did not want to take the risk.

Increased Awareness and Education

Recommendations for increased FA education and management continue to be a priority. In 2021, Waserman and colleagues recommended FA training for teachers and other school staff in FA management as one element of their practice guidelines for FA in schools. In Sanagavarapu's (2025) recent scoping review, this researcher identified a need for school staff education and recommended that education should not only focus on physical safety and FA management but also address psychosocial supports that may be needed for students with a FA. Santos also identified that teachers recognized their own knowledge gaps in FA management and wanted a standardized approach to education and training (2022, 2023), while Feldman et al.'s (2022) and research identified a need for formal school-based allergy program targeting students with and without food allergy. Similarly, Ross et al. (2022) conducted an online survey of education needs within the school and identified a need for FA education targeted at the whole school community. In this study, participants echoed the aforementioned research that more education and awareness about FA for school staff and students is still needed and that FA education needs to extend to the wider school community to include the parents of children without FA. The rationale for including parents was that increasing their knowledge about FA may contribute to greater policy adherence and enhanced empathy. Parents also recommended that education be provided for school volunteers or paid staff that supervise students at lunch or are involved in any way with serving food to students.

Maintain Nut-Aware Policies in Schools

All children, youth, and parents in this study recommended maintaining nut-aware policies in schools, with particular emphasis for younger school-aged children. As discussed in the previous section, participants had a realistic awareness that policy could not be perfectly implemented or provide 100% safety, yet all believed it was important to maintain. Some children articulated that they felt normal and safe at school because nuts were not allowed. Youth reflected on the importance of having a nut-free environment when they were younger as it contributed to their sense of safety at a time while they were still learning to manage their own FA and were more reliant on caregivers and teachers for allergen safety. Further, it was noted that younger children engage in messier behaviours (e.g., food on hands and face, crumbs on table and chair) and may inadvertently put things in their mouth (e.g., chewing on shared pencils), increasing their risk for cross-contamination when allergenic foods are present in the environment.

The recommendations to keep nut-aware policies in schools do not align with the current recommendations from Food Allergy Canada (n.d.) and practice guidelines (Waserman, 2021). That said, this is valuable feedback which Canadian schools should take under advisement before considering a reversal of policy. It is also worth reiterating that the practice guidelines recommending against food bans are based on a conditional recommendation, or that which has a very low certainty of evidence. Further, the two primary studies by Bartnikas et al. (2017) and Cherkaoui et al. (2015) that are frequently cited as research demonstrating that nut-free school policy are ineffective are both methodological flawed. Given this, it may be prudent for schools to keep nut-aware policies in place until more rigorous research can provide further guidance.

Strengths

This study's use of theory and research methodology offered many strengths; most notably is its conceptual clarity. As mentioned in the literature review in Chapter 3, many located published qualitative research studies about FA lack a clearly articulated theoretical perspective guiding research design. Moen et al. (2019) noted in their qualitative review of parent experiences of raising a child with a FA, that although the articles included in the review were assessed to be of high quality, only 26% of these studies acknowledged the philosophical underpinning of their chosen research methods. In response, the use of Crotty's (1998) scaffolded approach allowed for the research design to be grounded in a coherent ontology, epistemology, theory, and research methodology all of which aligned with and complement the purpose of the research. See Appendix B for a graphic summary of the research design.

To my knowledge, this is the first study to integrate Bronfenbrenner's EST (1977), van Manen's hermeneutic phenomenology (2014), and ecomaps, an arts-based approach, to explore FA experiences from the perspectives of children, youth, and their parents. This triangulated approach demonstrated how each theoretical approach and method were complementary to the research purpose and strengthened both the data collection and analysis. In particular, the use of ecomaps emerged as a key strength. This arts-based activity was helpful for parents, children, and youth to visually depict their experiences and facilitated discussion during participant interviews. In addition to supporting dialogue, ecomaps provided a meaningful source of data. Not only did the ecomaps highlight the various microsystems of participants, and their mesosystems, it also provided meaning to the nature of relationships and feelings towards these relationships and environments (e.g., strong connection, stressful relationship because of FA).

This study was informed by hermeneutic phenomenology and the use of van Manen's (2014) five existentials allowed the data to be presented in a clear and consistent manner capturing the depth of experiences. Beyond capturing lived experience, this study strengthens understanding of the practical implications and offers participant-informed recommendations that may inform policy, education, and practice within the school environment. An example of this was the identification of an identified gap in FA training for individuals responsible for serving food or supervising students during mealtimes at school, underscoring the importance of ensuring the individuals in these roles receive adequate education and training to promote school wide allergen safety.

Limitations

Several limitations of this study's sample are acknowledged. This purposive sample consisted of 21 participants, including 8 mothers, 4 fathers, 4 children, and 5 youth. While this sample allowed for an in-depth exploration of lived experiences consistent with hermeneutic phenomenology, it does not capture the full range of experiences across diverse populations and school contexts. Participation was limited to English speaking children, youth, and parents; therefore, Canadians with varied languages and/or cultural backgrounds were not adequately represented. While this study was open to all Canadians across the country, participation was limited to two geographic regions in Canada, again limiting the transferability of findings to other provinces and territories. Although multiple recruitment strategies were employed, all children and youth were recruited because of initial parent interest. In not collaborating with schools for recruitment, it may have limited children and youth participation. Finally, parent participants reported a relatively high educational attainment, with all having completed high

school and held a college or university degree, and half of annual household incomes reported exceeded \$150,000. Together, this suggests a higher socioeconomic status, and as such, this sample may not be representative of experiences of those with less education and financial resources. Despite the limitations, this research does address an identified gap in the literature, provides valuable insight into the experiences of FA for some children, youth, and their families living in Canada.

Recommendations

Policy Recommendations

Food labelling, in particular PALs such as “may contain”, requires clearer definition in Canada to better assist families in making safe food choices. Participants in this study, as well as the parents in prior research (Abrams et al., 2020), have drawn attention to PALs as ambiguous and misleading. Rather than offering reassurance, families are required to make judgement calls about food safety adding undue stress and uncertainty. The variability described by participants in how they approached “may contain” labels further underscore the need for greater clarity and consistency. Further, teachers and support staff may be tasked with making decisions about food safety in the classroom, including how to interpret PALs. This is a call for a coordinated effort by industry and regulators, in consultation with Food Allergy Canada, other leading experts, to address the expressed concerns of families with FA to work to lessen the ambiguity in PAL to better guidance and support for families to make informed decisions about safe food choices.

This study highlights the need for a pan Canadian approach to school-based FA policy. Every Canadian student with FA should be afforded the same FA protections regardless of their geographical location. However, the current policy landscape is complex, as provinces

enact legislation, school boards develop policies, and individual schools implement these policies, allowing for local adaptation. While such flexibility may be necessary to address contextual differences, it has contributed to variability in protections across jurisdictions. Parents should not feel compelled to seek out schools based on the perceived strength FA policies and practices, nor should families without school choice face inconsistent protections. At present, provincial legislation and existing resources (Food Allergy Canada, 2019, 2021; Waserman et al., 2021) provide a foundation upon which a national approach could be developed. That said, based on this research study, one exception to current recommendations warrants emphasis. Given the recommendations from children, youth, and parents in this study, alongside a paucity of strong, rigorous evidence supporting the removal of nut-free policies in Canada, maintaining nut-free or nut-aware policies in schools remains is recommended as a cautious and prudent approach at this time.

In a recent development, Senator Andrew Cardozo introduced Bill S-247 to the Senate, an Act to establish a framework that “sets out a coordinated national approach to reduce the incidence and risk of FA, improve access to timely diagnosis and evidence-based care, strengthen education and awareness, and enhance safety and quality of life for Canadians with FA” (Food Allergy Canada, 2026, para 2). If passed, this legislation would require the federal government to collaborate with provinces, territories, health care professionals, and patient groups to develop a coordinated national approach to FA. Two national organizations that bring together the health and education sectors may provide a pathway for advancing a Canadian FA strategy as it relates to FA management in the school environment. The Pan-Canadian Joint Consortium for School Health (JCSH; 2018) was established by provincial, territorial governments to bridge health and education systems to work together to improve the health,

well-being, and academic outcomes in school-aged children. Another option that might be well-positioned to support the development of a national approach to FA is the Canadian Healthy Schools Alliance. This is a national collaboration of stakeholders from the health and education sectors committed to advancing healthy school communities across Canada (Storey, n.d.). Collaborating with organizations such as these may provide a pathway toward advancing a coordinated, evidence-informed national FA strategy in Canadian schools.

Recommendations for Practice and Education

The recommendation to increase FA awareness and education in schools is not new, but one that children, youth, and parents in this study have stressed is still needed so that they may trust and feel confident in the school's ability to safely manage FA. School leadership must be prepared to set the tone in their schools and any efforts to improve FA awareness must involve the entire school community. To reach the wider school community, FA safety expectations need to be reflected in the school's website, the student/parent handbook, reiterated in school signage, and all school communications. This awareness needs to extend beyond telling parents no nuts are allowed; providing context and practical guidance on how to adhere to school policy would be helpful in addressing compliance.

Recommendations for education and practice to provide optimal safety and inclusion for families with FA within the school environment must be rooted in well-implemented routines and allergy competence from all school staff ranging from school administrators, teachers, school counsellors, and anyone responsible for serving or supervising students at mealtimes. The development of a standardized approach to FA education and training, including annual EAI training, is also recommended by Santos et al. (2023). A standardized approach is necessary to ensure that the expectations for safe care for students with FA should not vary by school district

or leadership preferences. This approach should draw on existing resources such as provincial legislation, Food Allergy Canada guidelines (2019), expert practice guidelines (Waserman et al., 2021), and as well, new and emerging research that includes the perspectives of children, youth, parents, and teachers. Further, a standardized approach to education should also include the psychosocial impacts of FA on families so that they may understand and prioritize mental health (Martinez et al., 2023; Huddleston et al., 2020).

To address the safety and psychosocial needs of students with FA, Martinez et al. (2023) recommends collaborating with students with a FA and their parents, and health care providers. Creating advisory roles for students with a FA and/or their parents in schools can draw on their knowledge and lived experiences of FA and help to better inform creating a safe and inclusive school environment. Schools with on-site counsellors should be included in FA education so that they may be equipped to understand and recognize allergy-related anxieties, or instances of bullying, social exclusion, or isolation. School counsellors can provide meaningful support for students experiencing allergy-related anxieties or concerns about social exclusion. They are also well-positioned to address FA-related bullying in the school and provide supports for families that do experience bullying in the school setting.

Collaboration with public health to strengthen supports for FA would also benefit the school community. According to Sanagavarapu et al. (2025), teachers reported difficulty in managing FA without support from full-time on-site school nurses. The role of the school or public health nurse is ideally suited to provide education about FA and support the physical and psychosocial needs of students with a FA. At present, Canadian public health nurses play a variable and limited role in supporting schools in student's emergency action plans and EAI training due to high nurse to school ratios (Buduhan & Woodgate, 2021). In an expanded role,

with greater school presence, school nurses could play a more integral role in the preventative management, emergency preparedness, and the development and implementation of school-wide education initiatives focusing on FA awareness, safety, and inclusion (Buduhan & Woodgate, 2021; Simeone et al., 2025). Further, nurses in schools could help alleviate the burden placed on teachers, who are not health care professionals, to feel prepared and confident to manage FA in their classrooms. Alongside school leadership, school nurses can help set the tone to promote FA safety and inclusion in the school setting.

Future Research

This study has addressed a knowledge gap about the lived experiences of children and youth with a FA, along with their parents offering an updated Canadian perspective from multiple viewpoints. That said, expanding this study to include a larger sample size to include a more diverse population and participants across all provinces and territories are needed to offer a true pan-Canadian perspective. Building on this research, future research to address other gaps in knowledge about FA in the school environment by including different perspectives within the school environment is still necessary. To more fully understand FA in the school context, involving school staff spanning elementary through high school would be beneficial. Given that parents in this study believe school principals should set the tone for leadership in FA safety within schools, future research should explore principals' experiences and information needs to support this role. Additionally, research regarding FA awareness and management focusing on students without a FA and their parents would provide valuable insights into their current knowledge and attitudes towards FA safety in schools to better address their educational needs.

Additional research focusing on school policy in Canada is also warranted. Given the recommendations for standardized school policy and enhanced policy adherence, it would be

beneficial to understand how current FA policies still differ across Canadian schools and what types of strategies may be best employed to promote policy adherence within the schools.

Finally, as study participants felt that nut-free school policies remain an important part of school safety, particularly in the younger grades, more rigorous research is needed to assess the effectiveness of these policies.

Knowledge Translation

Knowledge translation (KT) is an essential part of health and social science research (Ackerley, 2017) and planning for strategies to disseminate research is an important aspect of the research process. (Canadian Institute for Health Research [CIHR], n.d.). The CIHR defines KT as the “exchange, synthesis and ethically-sound application of knowledge-within a complex system of interactions among researchers and users-to accelerate the capture of benefits of research for Canadians, through improved health, more effective services and products, and a strengthened health care system” (2015). Knowledge dissemination refers to sharing findings from research by tailoring the message for use with the appropriate audience.

KT strategies for this study will focus primarily on traditional methods such as academic presentations and publications; however, I also have plans for community dissemination strategies. Oral and poster presentations at conferences in education, nursing, and those focused on FA will be considered as knowledge translation strategies. Publications in peer-reviewed academic journals such as *The Journal of School Nursing* or the *Qualitative Health Research* will be an area of focus. Community-based dissemination strategies for schools may combine active strategies such as presentations in the classroom and/or passive strategies such as research summaries sent through school email. Each strategy can be adapted to the local context as appropriate. All families who participated in this study have indicated that they would like to

receive a summary of results. Once completed, a research summary and infographic will be sent to them through the emails provided to me at the study onset. Other appropriate dissemination strategies may be considered in the future and in consultation with my research advisor.

Concluding Remarks

This qualitative research study is significant for several reasons. First, it contributes to the breadth and depth of knowledge about FA related experiences of children, youth, and their parents with an emphasis on the school environment. By offering a contemporary Canadian perspective, this study adds to existing literature that is grounded in philosophical assumptions, theory, methodology, and methods of which are all in alignment. This study is novel in its use of van Manen's hermeneutic phenomenology and Bronfenbrenner's (1977) EST to understand FA related experiences. Additionally, this appears to be the first study to integrate van Manen's (2014) hermeneutic phenomenology with the use of ecomaps, an arts-based activity, to explore the lived experiences of FA from multiple perspectives.

Although recently there has been more research in Canada about FA in schools, the focus has varied. Research areas have ranged from exploring policy needs from parents' perspectives (Abrams, 2020), teachers' perspectives of school management and their learning needs (Santos et al, 2023), to the experiences of children in elementary and middle school (Feldman et al., 2022). This study, however, brings together perspectives from children, youth, and parents, addressing a broad range of topics that span their lived experience at home, in the community and in school, as well as provides participant recommendations for policy and practice. Further, seeking the perspectives of both children and youth offers insights not only to their current experiences, but also how their experiences shift over time, developmental age, and through school transitions. This study has highlighted the need for clarity on precautionary food labels, identified an

important policy-to-practice gap in lack of training for lunchtime staff and volunteers for identifying students with FA and how to manage anaphylaxis, and demonstrated a potential shift in acceptance of FA as bullying was not experienced by these children or youth at school. Further, this study has demonstrated that mothers of children with a FA often advocate for their child through volunteer roles at school and find support through online FA groups. Guided by the overarching theme, *Striving for Safety*, as the essence of the lived experience of FA, this research amplifies the voices of children, youth, and parents living with a FA, underscoring the importance of using their experiences to inform school policy, education, and future research, with the shared goal of fostering relationships and environments that promote safety and inclusion.

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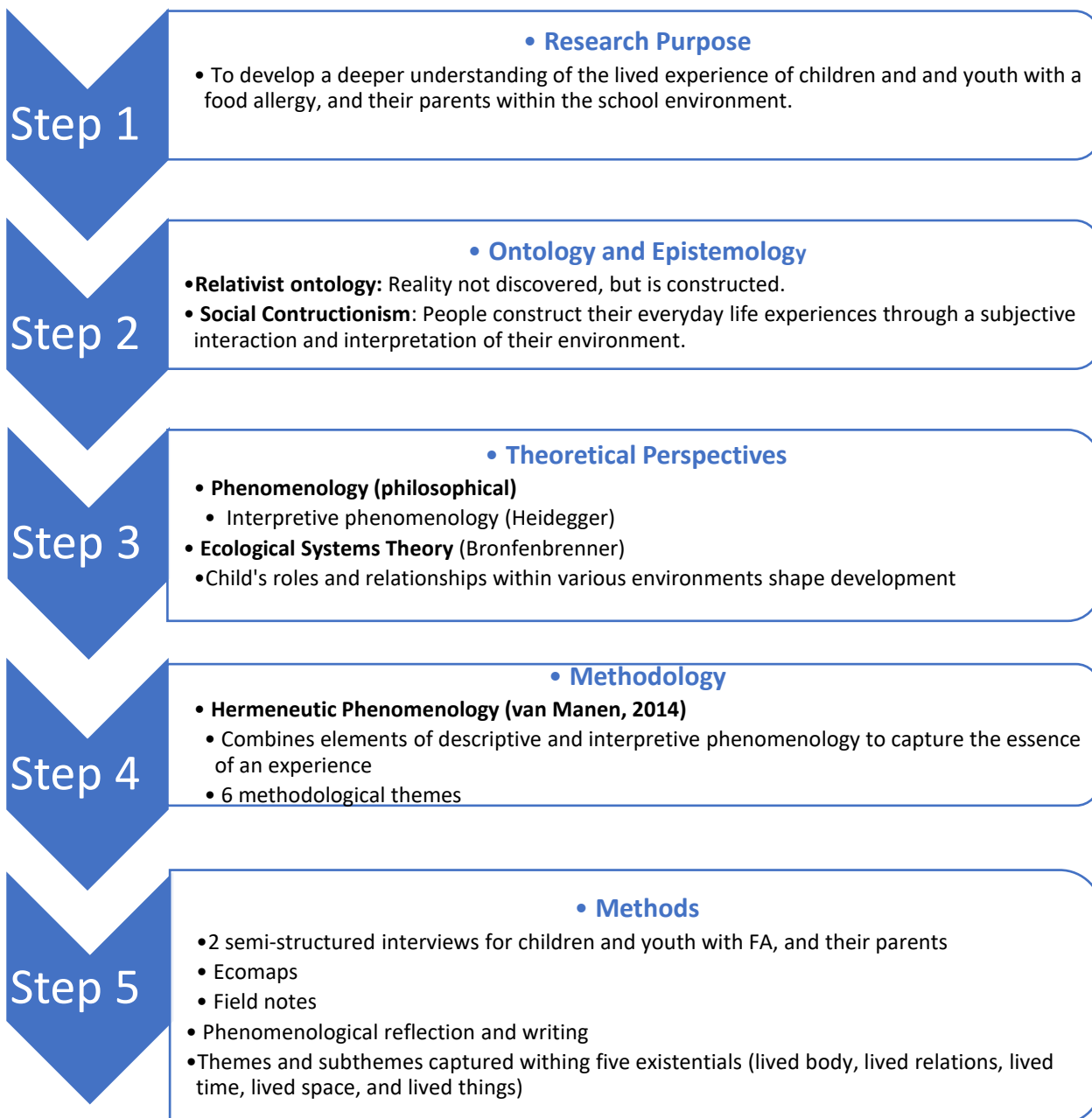
Appendix A

Scaffolded Research Process (Crotty, 1998)



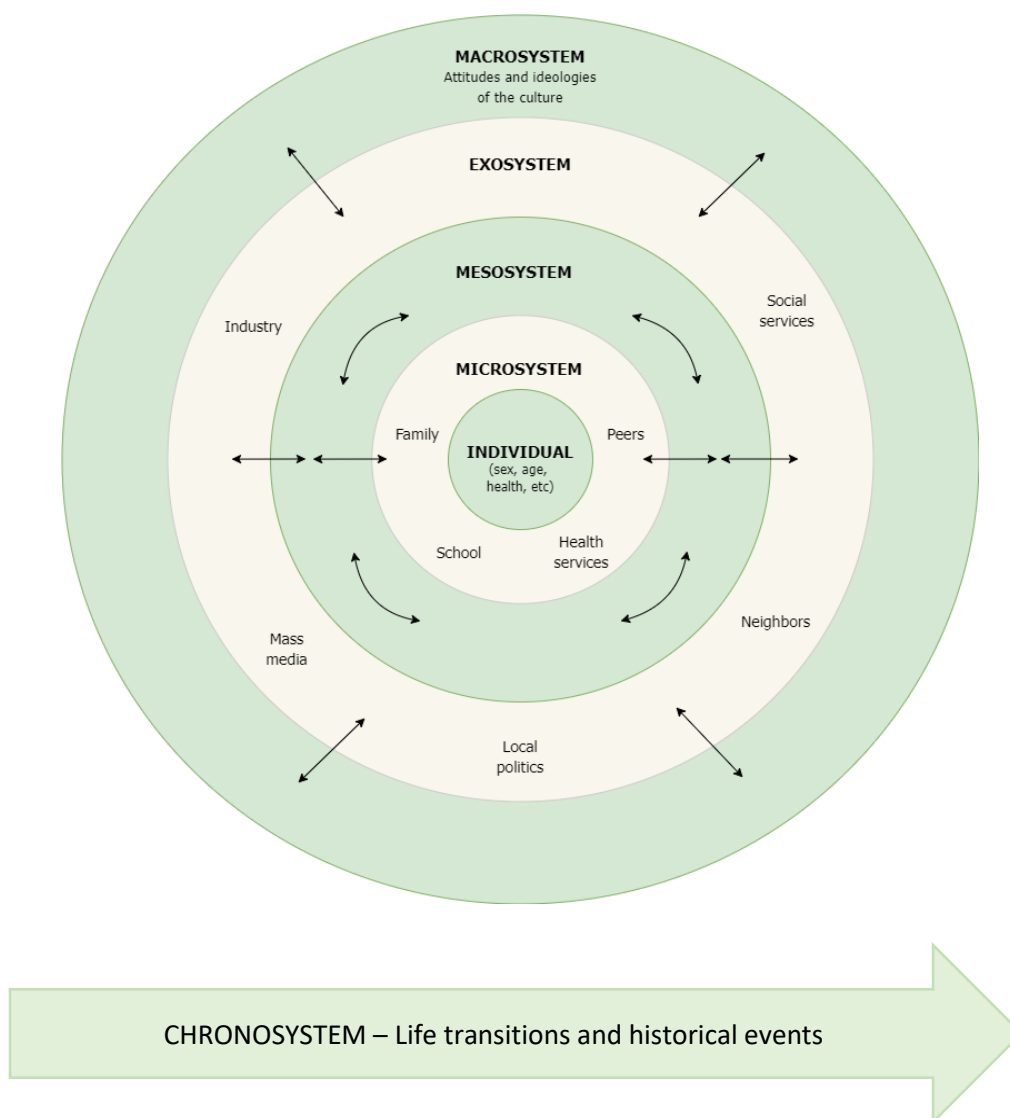
Appendix B

Summary of Research Design



Appendix C

Ecological Systems Theory



Note. Adapted from *Bronfenbrenner's Ecological Theory of Development*, by Abbeyelder, 2022, Wikimedia Commons

(https://commons.wikimedia.org/wiki/File:Bronfenbrenner%27s_Ecological_Theory_of_Development.png), licensed under CC BY-SA 4.0.

Appendix D

Original Recruitment Poster

RESEARCH PARTICIPANTS NEEDED

STUDY TITLE: THE LIVED EXPERIENCES OF YOUTH WITH A FOOD ALLERGY & PARENTS WITHIN A SCHOOL ENVIRONMENT

WHAT IS THE STUDY ABOUT?

- We want to hear your voice to better understand what it is like to be a youth with a food allergy & their parents at school.



ELIGIBILITY

- Youth across Canada, aged 12-17, who have a food allergy & attend school
- Parents of a youth, aged 12-17, with a food allergy



WHAT CAN YOU EXPECT?

- Take part in 2 virtual interviews & 1 art activity (In-person optional in the Okanagan, BC or Winnipeg, MB)
- Participation is confidential & voluntary
- \$25 gift cards are given for each interview (max \$100 per family)



TO PARTICIPATE OR FIND OUT MORE

PRINCIPAL RESEARCHER: Vanessa Buduhan BA BN MN PhD Candidate

CONTACT:



RESEARCH ADVISOR:

Dr. Roberta L. Woodgate RN PhD, Distinguished Professor, College of Nursing, University of Manitoba

CONTACT:



University of Manitoba | Rady Faculty of Health Sciences

This study has been approved by the Research Ethics Board at the University of Manitoba, Fort Garry campus (2024)

Appendix E

Updated Recruitment Poster

RESEARCH PARTICIPANTS NEEDED

STUDY TITLE:

THE LIVED EXPERIENCES OF CHILDREN OR YOUTH WITH A FOOD ALLERGY & THEIR PARENTS AT SCHOOL

WHAT IS THE STUDY ABOUT?

- We want to better understand what it is like to be a child or youth with a food allergy & their parents at school.



ELIGIBILITY

- Children or youth across Canada (ages 8-19) who have a food allergy & attend school
- Parents of a student (ages 8-19) with a food allergy



WHAT CAN YOU EXPECT?

- Take part in 2 virtual interviews & 1 art activity (In-person optional in the Okanagan, BC or Winnipeg, MB)
- Participation is confidential & voluntary
- \$25 gift cards are given for each interview (max \$100 per family)



TO PARTICIPATE OR FIND OUT MORE

PRINCIPAL RESEARCHER: Vanessa Buduhan BA BN MN PhD Candidate

CONTACT:



RESEARCH ADVISOR:

Dr. Roberta L. Woodgate RN PhD, Distinguished Professor, College of Nursing, University of Manitoba

CONTACT:



University of Manitoba | Rady Faculty of Health Sciences

This study has been approved by the Research Ethics Board at the University of Manitoba, Fort Garry campus (2024)

Appendix F



Child or Youth with a Food Allergy and Their Parents Experiences at School

I.D.

No.:

Date:

Demographic Profile Parent or Caregiver

1. What is your date of birth? (dd/mm/yyyy) _____
2. What is your gender identity? (Check/Circle all that may apply)
 - ☐ Agender
 - ☐ Female
 - ☐ Male
 - ☐ Transgender
 - ☐ Two-Spirit
 - ☐ Other or additional gender identity (specify): _____
 - ☐ Prefer not to answer
3. Which pronouns would you prefer I use? (Check all that may apply)
 - ☐ She/her/hers
 - ☐ He/him/his
 - ☐ They/them/their
 - ☐ Prefer to self-describe: _____
 - ☐ Prefer not to answer
4. Which province or territory do you live in?

☐ Alberta	☐ Nunavut
☐ British Columbia	☐ Ontario
☐ Manitoba	☐ Prince Edward Island
☐ New Brunswick	☐ Quebec
☐ Newfoundland and Labrador	☐ Saskatchewan
☐ Northwest Territory	☐ Yukon
☐ Nova Scotia	
5. Do you live in a rural or urban area?
 - ☐ Rural; specify _____
 - ☐ Urban; specify _____

6. What is your marital status?
- | | |
|--|--|
| ☐ Single, never married | ☐ Widowed |
| ☐ Married | ☐ Living together |
| ☐ Separated or Divorced | ☐ In a relationship, living apart |
7. What is your highest level of education completed?
- | | |
|---|---|
| ☐ Grade 8 or less | ☐ Some university |
| ☐ Some high school | ☐ Bachelor's degree |
| ☐ High school diploma | ☐ Master's degree |
| ☐ Some college | ☐ PhD |
| ☐ College degree/diploma | ☐ Prefer not to answer |
8. What is your combined family income before taxes per year?
- | | |
|---|--|
| ☐ Below \$25,000 | ☐ \$100,001-\$125,000 |
| ☐ \$25,001- \$50,000 | ☐ \$125,000- \$150,000 per year |
| ☐ \$50,001- \$75,000 | ☐ Over \$150,000 |
| ☐ \$75,001-\$100,000 | ☐ Prefer not to say |
9. What ethnic group do you identify with (Check all that may apply)
- ☐ Indigenous
 - ☐ Latina/Latino/Hispanic
 - ☐ Black
 - ☐ Middle Eastern
 - ☐ East Asian
 - ☐ Central Asian
 - ☐ South Asian
 - ☐ Southeast Asian
 - ☐ West Asian
 - ☐ Caucasian
 - ☐ Other; please specify: _____
10. If applicable, please indicate your Indigenous ancestry:
- ☐ First Nation
 - ☐ Inuit
 - ☐ Métis

11. For all the people in your home, please indicate their age, gender, school grade (if applicable), and/or occupation (if applicable), and relationship to you.

	Age	Gender	School Grade	Occupation	Relationship to You
Person 1					
Person 2					
Person 3					
Person 4					
Person 5					
Person 6					
Person 7					
Person 8					

12. When was your child with a food allergy born? (dd/mm/yyyy) _____

13. What age did your child get diagnosed with a food allergy? _____

14. What is your child's food allergy(s) (e.g., peanuts, tree nuts, milk, eggs, fish)?

15. Does your child with a food allergy have any other health conditions? Please list.

16. Does your child have epinephrine auto-injector at school (e.g., Epi-Pen or Allerject)?

Check all that apply.

☐ Yes, on person

☐ Yes, in school bag

☐ Yes, in school office

☐ Yes, other

(specify): _____

☐ No

☐ Not sure

17. Are you aware if your child's school supplies stock epinephrine for emergencies?

☐ Yes

☐ No

☐ Unsure

18. Are you aware of your school's food allergy policies?

☐ Yes, please describe (e.g., nut-aware, nut-free, food allergy table, other food bans)

☐ No

☐ Unsure

19. Was your child's food allergy a consideration in choice of school for your child?

20. On average, how many auto-injectors do you purchase per year? _____

21. Do you pay for these directly or does your insurance cover the cost?

22. Do you keep expired auto-injectors? If so, why (e.g., "just in case", too expensive to replace)?

23. Has your ever child experienced an allergic reaction or anaphylaxis at school? If so, were they given epinephrine? (e.g., Epi-Pen or Allerject?)

24. How did you hear about this study?

25. Is there anything else that you would like to tell us about yourself or your family?

Appendix G



Child or Youth with a Food Allergy and Their Parents Experiences at School

No.:

Date:

I.D.

Demographic Profile of Child or Youth

1. What is your date of birth? (dd/mm/yyyy) _____
2. What is your gender identity? (Check/Circle all that may apply)
 - ☐ Agender
 - ☐ Female
 - ☐ Male
 - ☐ Transgender
 - ☐ Two-Spirit
 - ☐ Other or additional gender identity (specify): _____
 - ☐ Prefer not to answer
3. Which pronouns would you prefer I use? (Check all that may apply)
 - ☐ She/her/hers
 - ☐ He/him/his
 - ☐ They/them/their
 - ☐ Prefer to self-describe: _____
 - ☐ Prefer not to answer
4. Which province or territory do you live in?

☐ Alberta	☐ Nunavut
☐ British Columbia	☐ Ontario
☐ Manitoba	☐ Prince Edward Island
☐ New Brunswick	☐ Quebec
☐ Newfoundland and Labrador	☐ Saskatchewan
☐ Northwest Territory	☐ Yukon
☐ Nova Scotia	
5. Do you live in a rural or urban area?
 - ☐ Rural; specify _____
 - ☐ Urban; specify _____

6. What grade in school are you in ? _____
7. Who do you live with?
- ☐ Mom full-time
 - ☐ Dad full-time
 - ☐ Mom and Dad together full-time
 - ☐ Mom part-time and Dad part-time
 - ☐ Grandparent
 - ☐ Other (specify): _____
 - ☐ Prefer not to answer
8. Do you have any siblings?
- ☐ Yes, how many? _____ ☐ No
9. What age did you get diagnosed with a food allergy? _____
10. What is your food allergy (e.g., peanuts, tree nuts, milk, eggs, fish)?
- _____
11. Do you have any other health conditions? (e.g., asthma, anxiety) Please list.
- _____
12. Do you have an epinephrine auto-injector at school (e.g., Epi-Pen or Allerject)? Check all that apply.
- | | |
|--|---|
| ☐ Yes, on person | ☐ Yes, in school bag |
| ☐ Yes, in school office | ☐ Yes, other |
| (specify): _____ | |
| ☐ No | ☐ Not sure |
13. How did you hear about this study?
- _____
14. Is there anything else that you would like to tell us about yourself or your family?
- _____

Appendix H

Interview Guide for Parents/Caregiver



Interview Guide for Parent/Caregivers of a Child /Youth with a Food Allergy

Introduction

1. Could we begin by telling me a bit about yourself/yourselves?
 - *Interviewer may ask additional questions such as; can you tell me about your family, your child/children. Once the interviewer feels that the parent(s)/caregiver(s) are comfortable, the interviewer will proceed.*

Let's take some time to review the Eco-Map that you created that represent the relationships that shape you and your lives.

2. Can you tell me about when/how your child was diagnosed with a food allergy?
 - Describe your experiences around the time of diagnosis.
 - How did these experiences make you feel?
3. Becoming informed about a food allergy and how best to manage and protect your child can be a big learning curve.
 - Where did you get the most education/support (allergist, nurses, internet, other)?
 - Can you describe your learning journey from where it began to where it is now?
 - How would you describe your role of a parent/caregiver in advocating for your child?
 - Can you tell me about a time when this went well or not so well?
4. Can you tell me what is like being a parent/caregiver of a child with a food allergy?
5. From my experience, having a child with a food allergy usually requires major shift in the day to day. Can you tell me about your experiences about some of the changes you have had to make?
 - Food purchases/food labelling
 - Food preparation
 - Socializing – change in relationships?
 - Child care

6. How do you believe food allergies have impacted your child's siblings?
 - At home (relationships with siblings, peers)
 - In school (relationships with siblings, peers)
 - In the community (restaurants, family outings)

7. Shifting to more of a school focus, can you tell me a what it was like to send your child to school for the first time?
 - Were you aware of school food allergy policies before starting school?
 - Did these policies impact your choice of school for your child?
 - Did you meet with your teacher/principal/school nurse to discuss your child's allergies? Did those meetings make you feel safer/supported/worried?
 - With each passing school year, do your feelings/worries ease? Why do you think that may be? (older, familiar with school/teachers?)

8. Has your child ever had an allergic reaction/anaphylaxis at school? Can you tell me about that experience.

9. Describe the level/depth of communication within the school about food allergy (If applicable, how does this differ from your child(s) that do not have a food allergy?
 - Teachers
 - School administration
 - Parents

10. What are the factors that negatively impact your or your child's experiences related to their food allergy at school?
 - Has your child ever experienced teasing or bullying as a result of their food allergy? If so, describe how you, your child and the school responded.
 - Have you as a parent received any negative comments or experiences as a result of your child's food allergy from anyone at school (teachers, students, parents)?
 - Describe how these comments made your child/you feel in that moment?
 - Has your child ever felt excluded or isolated at school from activities that involve food as result of their food allergy? Excluded from birthday parties?
 - Describe your experiences and feelings.
 - Has your child's food allergy impacted their ability to fully participate in any school activities (lunchtime, celebrations, special projects involving food, field trips)?
 - Describe these experiences and talk about how they have shaped future actions/decisions about your child's participation?
 - How have these experiences impacted how you and/or your child have reacted moving forward?

11. What are some of the factors that positively impact you or your child's experiences related to their food allergy at school?

- Describe your experiences that make you/your child feel supported safe at school? (policies, friends, teachers, parents)
 - Do you have any recommendations that could improve the school environment for child with food allergies?
12. How do you feel your school's food allergy policies impact these experiences for you or your child?
- Are you aware of the school's food allergy/management policies? Do you feel they are sufficient?
 - Are there any experiences that you can tell me about how these school policies positively or negatively impacted your child?
 - Epi-Pens/Alleject in school – how many, where are they stored, school stocked?
 - How have teachers responded to you/your child in accommodating food allergies in the classroom?
 - How have parents in the school community responded to accommodating food allergy policies?
 - Do you have any suggestions to change food policies to provide a safer environment for your child?
13. Can you describe how your experiences with food allergy changed with COVID-19?
- Day to day management?
 - School specific changes?

Ending Questions

14. Can you share with me what made you decide to take part in this study?
15. Is there anything else you would like to talk about that we did not get to discuss?
16. Are there any other questions we could ask parents/caregivers participating in this study that you believe would be helpful to this study?

Concluding Remarks/Wrap Up

- ☐ Questions?
- ☐ Thank everyone for their participation.
- ☐ Reminder that anonymity will be protected, review strategies identified earlier.
- ☐ Distribute incentives (gift cards)

Appendix I



Interview Guide for Child or Youth with a Food Allergy

Introduction

Tell me a bit about yourself.

1. You have a food allergy to _____. Can you tell me what that's like for you?
2. Have you ever had an allergic reaction to that food? (If yes, can you tell me what happened to you? Do you remember how that made you feel?)
3. What is it like to have a food allergy at home?
4. How do your parents help you manage your food allergy?
5. How do you manage your own FA?
6. If you have a brother or sister, do they help you or look out for you because of you allergy?
7. My daughter has a food allergy to all nuts – she says it can “suck” sometimes. Do you know what she might mean by that? Do you agree? Can you describe an example?
8. Are you able to eat out at restaurants or friends houses? Can you describe what that is like?
 - Can you tell me how you feel when you find out a restaurant/food is not a safe option for you and your family?
9. What are the rules about food allergy at your school?
 - How do you feel about these rules?
 - Do you agree with them? Why/why not?
 - Do you think they work?
 - Any rules you would like to see changed?
 - What happens when the rules are not followed at your school?
10. Do you have to wear an epi-pen or Allerject on you? Can you tell me some of the good things about wearing an epi-pen? What are the bad things about having to wear/carry an epi-pen?

11. At school, does having a food allergy mean you have to miss out on any fun stuff or are teachers pretty good at making sure everything is safe/allowed for all kids? (left-out?)
12. Have has any one teased or bullied you because you have of your food allergy?
13. At lunch, do you get to eat where you would like or is there a special place that you need to sit?
14. Have any of your experiences changed now that your are in middle/high school compared to when you were in elementary/junior school?
15. How has COVID-19 changed your experiences with your FA?
 - At home?
 - At school?
16. Do your teachers help you with your food allergy at school?
17. What would you like teachers or your school to know about what it is like having a food allergy?
18. What would you like your classmates to know about having an allergy?
19. How do your friends help you with your allergy at school or on play dates?

Ending Questions

20. What advice would you give teachers/your school to make it better for kids with food allergies?
21. What advice would you give another kid with a food allergy to help manage school and everyday life?
22. I know your parents probably asked you to sign up to talk about this. I want to thank you for coming and giving me such really honest and important answers. Is there anything else that you would like to share about having a food allergy as a kid?

Wrap Up

- Thank you so much for helping me with this study.
- Do you have any questions for me?
- Give incentives (gift cards)

Appendix J



Guide to Creating an Ecomap

What is an Ecomap?

An ecomap is a picture or graphic representation of relationships of networks of people (friends, family, community members) as well as events, places, or other things that may be important in your lives.

Ecomap Instructions

Each family will have the opportunity to draw an ecomap before or at the beginning of their interview. Please draw a circle (or whatever symbol preferred, e.g., box, heart) that shows the people, activities, and places that are and have been a part of your lives. You can also draw lines between the circles to indicate the level of connection that you have with each person, activity, or place on the map. Use different types of lines to demonstrate different types of connections. A legend is helpful to show what the circles/symbols and lines represent in your eco-map. You may choose to do one family ecomap or a separate ecomap for parent and child if that works better.

For parents, think about your relationships, activities, and/or places that were important to your life before your child was diagnosed with a food allergy. Did some of these get more or less important? Also, when your child started school, did these relationships, activities, and/or places change?

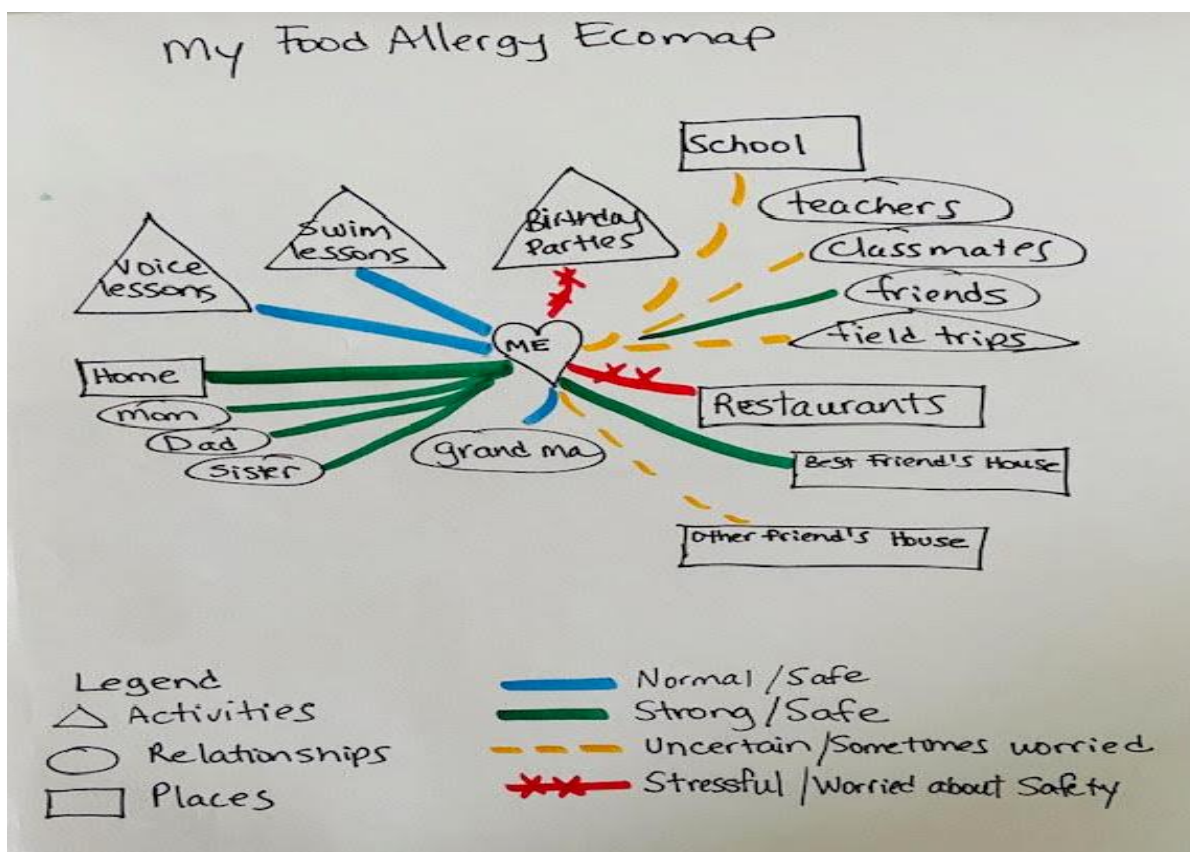
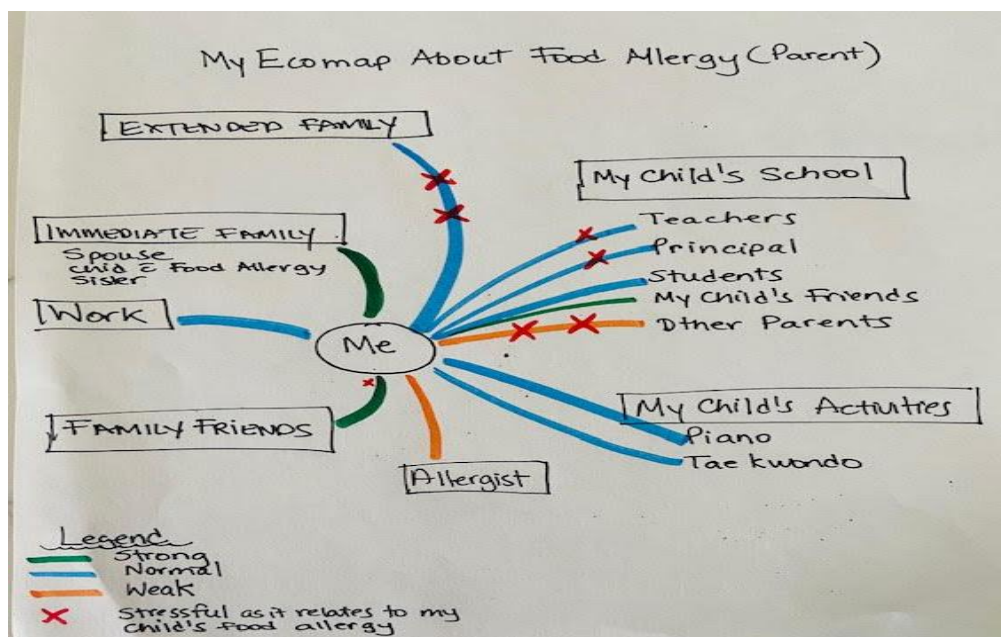
Examples of Symbols and Lines: You may choose to use circles to represent the people in your lives, squares to represent places, and triangles to represent activities. Connecting these with different lines can also be helpful in showing how important or strong of a connection these relationships are to you and your family. A solid or thick line may represent a strong connection, where a broken or dotted line may show a weaker or less important connection. Arrows along the lines can be used to point to the direction of the relationships or interest. A couple of examples of ecomaps have been included.

Remember, there is no right way to do this activity! Draw the ecomap in a way that works best for you.

What will the ecomap be used for?

The interviewer will use this ecomap to help guide the discussions about your experiences about food allergies in school. It may also be used during data analysis or for reporting the results of research.

Examples of Ecomaps



Appendix K

Field Note Guide

(Adapted with Permission from Dr. R.L. Woodgate)

1. Descriptive Notes

- **Environment**
- **Participants**

2. Theoretical Notes (Key Points of Interview)

3. Methodological Notes

4. Reflective Notes

Follow-up Question Development (after Interview 1 only)

Appendix L

Informed Consent Parents



University of Manitoba | Rady Faculty of Health Sciences

College of Nursing
University of Manitoba
89 Curry Place
Winnipeg, Manitoba
Canada R3T 2N2

ADULT PARENTS OR GUARDIANS (18 years old and older) INFORMATION AND CONSENT FORM

Title of Study: The Lived Experiences of Children or Youth with a Food Allergy and their Parents within a School Environment

Principal Investigator: Vanessa Buduhan BA BN MN PhD (Candidate)
Helen Glass Centre for Nursing, University of Manitoba
[REDACTED]

Thesis Advisor: Dr. Roberta Woodgate – Distinguished Professor
Helen Glass Centre for Nursing, University of Manitoba
[REDACTED]

Internal Member: Dr. Donna Martin – Professor, College of Nursing, University of Manitoba

External Member: Dr. Priya Mani – Associate Professor, Faculty of Education, University of Manitoba

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose of this Study

The purpose of this study is to understand and document the lived experience of child or youth with a food allergy and their parents (or guardians) in the school setting.

1. Understand the experiences and what it is like to be a child or youth (ages 8-19) who have a food allergy in school.
2. Understand the experiences and what it is like to be a parent (or guardian) of a child with a food allergy in school.
3. Understand how individual, relationships, community, and societal factors influence these experiences?
4. Understand how COVID-19's public health restrictions affected children or youth (ages 8-19) with a food allergy or their parents (or guardian)?
5. Identify recommendations/solutions that support children and youth with a food allergy and their parents (or guardian) in schools.

Participants Selection

You are being asked to participate in this study because of your own experiences as someone with a child that has a food allergy. We will be seeking to conduct individual interviews with about 10 children or youth and their parents.

Study procedures

If you take part in this study, we will request that you:

- 1) **Demographic Form:** We ask that you complete a short demographic form. We expect that this would take 5-10 minutes to complete.
- 2) **Ecomap Activity:** You will have the opportunity to draw an ecomap before or at the beginning of your first your interview. Ecomaps are graphic portrayals of social relationships or networks of individuals or families, as well as key events, places, or other important things in your life. You will be asked to draw circles that represent people, activities, and places that are and have been a part of your life. Then, you will be asked to draw different types of lines between the circles to indicate the degree of connection you have with each person, activity, or place you drew. This will take approximately 5-10 minutes to complete.
- 3) **Individual interview sessions:** Under the supervision of Dr. Woodgate, I, Vanessa Buduhan, will be doing two interviews about 1-2 months apart. The interviews will take place either virtually or in person depending on your preference and/or geographical location.

The interviews will be digitally recorded and transcribed to ensure the accurate reporting of the information you provide. The interviews will be transcribed by Ms. Buduhan. Once transcribed, the audio files will be deleted from the audio recorder and stored on a password-protected computer accessible only by Ms. Buduhan (principal investigator) and Dr. Woodgate (advisor). After the interview, the interviewer will write field notes. We expect that the interviews will take between 30 – 60 minutes to complete. Often, the first interview is longer than the second interview, but is different for everyone.

If you decide to participate in the study, a summary of the study will be provided to you on request.

Risks and Discomforts

There are some potential risks to you by participating in this research. It is possible that talking about your experiences might be emotional, embarrassing, or stressful for you. Resources for food allergy and/or mental health support will be made available to you if you feel like will be available if you feel like there is anything that has come up for you during the interview sessions that is upsetting.

If at any time during the interview sessions you feel uncomfortable with the questions being asked you can choose not to answer those questions, without any negative impact.

Benefits

There are no direct benefits to participating in this study. Short-term, the study will result in advanced knowledge on the experiences of children, youth and their parents about food allergy in schools including child, youth, and parent well-being, food allergy management, and school policy.

Recommendations to best support students with a food allergy and their parents' experiences at schools will be identified.

Costs

There is no cost to you to complete the demographic form, the ecomap, or to participate in the interviews.

Payment for participation

You will be given an honorarium for your participation in the interview sessions. For the first interview, parent(s) will receive a \$25 honorarium in the form of a gift card after you informed consent given and prior to your first interview. You will receive this even if you choose to discontinue the interviews. You will receive another \$25 gift card before the second interview. You will receive this even if you decide to withdraw from the study. Children or youth will also receive the same value of honorarium (2- \$25 gift cards) for a maximum of \$100 per family.

Confidentiality

We will do everything possible to keep your personal information confidential. Your name or other identifying information will not be used or revealed. A list of names and addresses of participants will be kept in a secure file, separate from any data, so we can send you a summary of the results of the study. Audio files of the interview(s) will be typed and used to prepare a report. The audio files and typed notes will be kept in a secure locked file cabinet and office. Only the principal researcher, Ms. Buduhan and her advisor, Dr. Woodgate will have access to them and know your name. All data from the study, including interview transcripts and field notes, will be stored on a password protected computer accessible only by research staff. This data will not have your name or any identifying information included. Your personal information may be disclosed if required by law (i.e., illegal or dangerous situations). If any of the participants talk about harming themselves, and/or are reporting abuse, then immediate action will take place to make sure the individual is safe and appropriate authorities will be contacted, along with Research Ethics Board at the University of Manitoba, Fort Garry campus.

The information collected in this study may be used to publish academic papers, presented in oral or poster presentations in academic or community settings. If the results of this study are presented in a meeting, or published, nobody will be able to tell that you were in the study. Please note that although you will not be identified as the speaker, your words may be used to highlight a specific point. The collection and access to personal information will be in compliance with provincial and federal privacy legislations. The information of this study may also be used other dissemination activities such as a research summary.

Some people or groups may need to check the study records to make sure all the information is correct. All of these people have a professional responsibility to protect your privacy. These people are:

- Research Ethics Board at the University of Manitoba, Fort Garry Campus which is responsible for the protection of people in research and has reviewed this study for ethical acceptability

If any of your research records need to be copied to any of the above, your name and all identifying information will be removed. No information revealing any personal information such as your name, address or telephone number will leave the University of Manitoba.

All records of your participation in this project, including paper records of transcripts, field notes, ecomap and demographic forms, will be destroyed seven years (11/2032) following the completion of the study.

Permission to Quote:

We may wish to use what you said to us, the exact words, directly in reports and publications resulting from this. Please let us know if we can do that by checking yes or no for each of the following sentences:

Researchers may publish documents that contain quotations by me under the following conditions:	
☐ Yes ☐ No	I agree to have my words (typed out) with a made-up name for myself instead of my own (so others won't know it is me who said these words) and any other family/friends that could be identifiable. Example – Richard, father, age 45, would change to a name like Mick, parent, age 45.
Researchers may publish your eco-map that consists of any words, images, photos, videos under the following conditions:	
☐ Yes ☐ No	I agree to have my ecomap used with changes only to my name, names of others, or places that could be identifiable. Example - Made-up names will replace real names as well, names of places would be replaced with a generic alternative. Example - St. Benedict's Middle School would be referred to as middle school.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary (your choice). You may refuse to participate, or you may withdraw from the study at any time prior the study completion (06/2025). We will give you the option of withdrawing from the study entirely, as well as options to withdraw from specific study activities, such as the ecomap activity. If you choose to withdraw from the study, we will verify with you if you would like any of your data included in the project. However, once the analysis is complete, we would be unable to remove your data. Contact Ms. Buduhan or Dr. Woodgate complete the withdrawal form (contact information below).

Questions

If any questions come up during or after the study contact the principal investigator Ms. Vanessa Buduhan at [REDACTED] or by email at [REDACTED]. You may also contact the research advisor, Dr. Roberta Woodgate at [REDACTED] or by email at [REDACTED].

Consent Signatures:

1. I have read all 5 pages of the consent form.
2. I have had a chance to ask questions and have received satisfactory answers to all of my questions.
3. I understand that by signing this consent form I have not waived any of my legal rights as a participant in this study.
4. I understand that my records, which may include identifying information, may be reviewed by the research staff working with the Principal Investigator and the agencies and organizations listed in the Confidentiality section of this document.
5. I understand that I may withdraw from the study at any time and my data may be withdrawn prior to publication.
6. I understand I will be provided with a copy of the consent form for my records.
7. I agree to participate in the study.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the Research Ethics Board at the University of Manitoba, Fort Garry campus at the University of Manitoba. If you have any concerns or complaints about this project, you may contact any of the above-named persons or the Human Ethics Coordinator at 204-474-7122 or humanethics@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Verbal consent given for the interview: Yes ☐ No ☐

Written consent if the participant chooses to sign:

Participant printed name: _____

Date _____
(day/month/year)

Participant signature: _____

-----*Principal Investigator Signs Below*-----

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Printed Name: _____

Date _____
(day/month/year)

Signature: _____

-----*Principal Investigator Signs Above*-----

The anticipated date of December 2025 is when a summary of the research results will be available.

I would like to have a copy of the summary of the project:

Yes ☐ No ☐

Mailing Address: _____

Email Address: _____

Appendix M

Child Assent

College of Nursing
University of Manitoba
89 Curry Place
Winnipeg, Manitoba
Canada R3T 2N2



University of Manitoba | Rady Faculty of Health Sciences

CHILDREN WITH A FOOD ALLERGY (Age 8-11) INFORMATION AND ASSENT FORM

Title of Study: Experiences of Children or Youth with a Food Allergy and their Parents at School

Principal Investigator: Vanessa Buduhan BA BN MN PhD (Candidate) – Graduate Student
Helen Glass Centre for Nursing, University of Manitoba
[REDACTED]

Thesis Advisor: Dr. Roberta Woodgate – Distinguished Professor
Helen Glass Centre for Nursing, University of Manitoba
[REDACTED]

This form is only one way of giving your okay to take part in the research. It will give you an idea of what the research is about and what we will be asking you to do. If you want to know more or do not understand, please let us know so we can help answer your questions.

Why do we want to talk to you?

You are being asked to take part in this research because you have a food allergy. We want to learn about what it is like for you to have a food allergy at school. We also want to learn from your parents too. We want to know if you would like to be in this study. This form tells you about the study. If there is anything you do not understand, please ask your parent, guardian or the researchers.

Why are they doing this study?

We want to learn more about children who have a food allergy from the ages of 8 to 19. We also want to learn from your parents (guardian) too. We want to know if there is anything we can do to make things better at school for kids with a food allergy and their parents.

What will happen to you?

If you want to be in the study, these things will happen:

1. We will ask you to fill out a paper called a Demographic Form. It will ask you questions about your age and grade at school. It should take about 5 -10 minutes. Ms. Buduhan, the researcher, or your parents can help you if you like.
2. You will then get to draw a picture about the most important things in your life, like your friends and family, activities you like to do, and places you like to visit. You can do this with your family. This is called an ecomap, and it will take you about no more than 10 minutes.
3. We will ask you questions. We will meet with you two times about a month in between. This means that we will ask you questions about your life, your health, and time at school. This should take about 60 minutes, but that depends on how much or how little you want to share. The interviews will be recorded. After the meeting, notes will be made about the meeting.

You will get a \$25 gift card before your first meeting. You will get this even if you want to stop the meeting or not want to do the other meeting. You will get a second \$25 gift card before the next meeting. You will get this even if you decide you wish to stop the research. If you want, we will send a write up about the research when it is done.

Will taking part in this research make you feel bad? Taking part in this will not hurt you. Sometimes it can be hard to answer questions about your health or your time at school. If you feel that way, you can stop the meeting and take a break or choose not to continue.

Will taking part make you feel better? Taking part in this may not make you feel better, but we may find out something that will help other children with a food allergy at school.

How will the information that you provide us be used?

What is learned from this research may be shown at other health or school meetings or written about in a magazine. The results of this research may also be shown through art (graphic short story).

Who will know what I did in the study?

We explained the research to your parents, and they said we could ask you if you want to be in it. All information given will be safely locked up. Your name will not be on any research and only Ms. Buduhan and her advisor will know that it was you who was in the study. The only time we will break privacy is if you or someone around you is in a situation where they could be hurt.

Some people or groups may need to check the records to make sure all the information is correct. Part of their job is to keep everything private. These people/groups are:

- The Research Ethics Board of the University of Manitoba which is responsible for the protection of people in research and has reviewed this study for ethical acceptability

Permission to Quote:

We may want to use what you said to us, the exact words, directly in our write-ups resulting from this. Please let us know if we can do that by checking yes or no for each of the following sentences:

Researchers may publish documents that contain quotations by me under the following conditions:	
☐ Yes ☐ No	I agree to have my words (typed out), and a made-up name will be used instead of my own. Example – If your name is Richard, a made-up name like Mick, would be used instead.
Researchers may publish your ecomap that consists of any words, images under the following conditions:	
☐ Yes ☐ No	I agree to have my ecomap used and a made-up name will be used for me and for any other people I may use in my eco-map. Example – If your name is Richard, a made-up name like Mick would be used and your friend Sam would have a made-up name like Pat.

Do you have to be in the study?

You do not have to be in the study. No one will be mad at you if you don't want to do this. If you don't want to be in this study, just say so. Even if your parents want you to be in the study you can still say no. And even if you say yes now, you can change your mind later. It is up to you. Please let Ms. Buduhan or Dr. Woodgate know if you change your mind at any time.

Questions

If any questions come up, please call, Ms. Buduhan at [REDACTED] or email [REDACTED]. You may also contact Dr. Roberta Woodgate at [REDACTED] or email at [REDACTED].

Assent Signatures:

I have had a chance to ask questions and get answers. I want to take part in this study. I know I can change my mind at any time.

Verbal assent given for the interview: Yes ☐ No ☐

Written assent if the participant chooses to sign:

Participant printed name: _____

Date _____
(day/month/year)

Participant signature: _____

-----Principal Investigator Signs Below-----

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their assent

Printed Name: _____

Date _____
(day/month/year)

Signature: _____

-----Principal Investigator Signs Above-----

If you would like, at the end of the study a summary will be provided by about December 2025.

I would like to have a copy of the summary of the project:

Yes ☐

No ☐

Parent (Guardian) Mailing Address: _____

Parent (Guardian) Email Address: _____

Appendix N

Youth Assent

College of Nursing
University of Manitoba
89 Curry Place
Winnipeg, Manitoba
Canada R3T 2N2



University of Manitoba | Rady Faculty of
Health Sciences

YOUTH WITH A FOOD ALLERGY (Age 12 -19) INFORMATION AND ASSENT FORM

Title of Study: The Experiences of Children or Youth with a Food Allergy and their Parents at School

Principal Investigator: Vanessa Buduhan BA BN MN PhD (Candidate) – Graduate Student
Helen Glass Centre for Nursing, University of Manitoba
[REDACTED]

Thesis Advisor: Dr. Roberta Woodgate – Distinguished Professor
Helen Glass Centre for Nursing, University of Manitoba
[REDACTED]

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand the information.

Why do we want to talk to you?

The researchers want to tell you about a study about the experiences of children or youth who have a food allergy and their parents at school. We want to know if you would like to be in this study. This form tells you about the study. If there is anything you do not understand, please ask your parent (guardian) or the researchers.

Why are they doing this study?

We want to learn more about children and youth who have a food allergy, ages 8-19. We would like to hear about your experiences about having a food allergy in school. We also would like to interview your parents (or guardian) to hear about their thoughts and experiences about food allergies in schools. You can still participate in the study even if your parents do not.

What will happen to you?

If you want to be in the study, these things will happen:

1. We will ask you to fill out a paper called a Demographic Form. It will ask you questions about your age and grade at school. It should take you 5-10 minutes to complete. You will not need to put your name on the form. Ms. Buduhan, the researcher, can help you.
2. You will then get to create a picture by drawing circles that represent the most important things in your life, like your relationships with your friends and family, activities you like to do, and places you like to visit. Then you will draw different lines between the circles to show how meaningful each of these people, activities, and places are to you. This is called an ecomap, and it will take you about 5-10 minutes to complete.
3. We will interview you two times about 1-2 months in between. This means that we will ask you questions about your life, your health, and your experiences. This should take about 60 minutes, but that depends on how much or how little you want to share. The interviews will be recorded. After the interview, the interviewer will write notes about what happened.

You will be given a \$25 gift card before you start your first interview. You will get this even if you choose to stop the interview or not do the second interview. You will get a second \$25 gift card before the second interview. You will get this even if you decide you wish to withdraw from the study. If you decide to participate in the study, a summary of the study will be provided to you if you want.

Will taking part in this study make you feel bad? The study will not hurt you. Sometimes it can be difficult to answer questions about your health or personal experiences. If you feel that way, you can stop the interview and take a break or choose not to continue.

Will taking part make you feel better? The study may not make you feel better, but the study may find out something that will help other children or youth with a food allergy at school.

How will the information that you provide us be used?

What is learned from this study may be presented at health or educational meetings or published in a professional journal. The results of this study may be presented in an arts-based format (e.g., graphic short story).

Who will know what I did in the study?

Any information you give to the researcher will be kept private. Your name will not be on any research paper and no one, but the research and advisor will know that it was you who was in the study. The only time we will break privacy is if you or someone around you is in a situation where they could be hurt.

Some people or groups may need to check the study records to make sure all the information is correct. All of these people have a professional responsibility to protect your privacy. These people/groups are:

- The Research Ethics Board of the University of Manitoba which is responsible for the protection of people in research and has reviewed this study for ethical acceptability

Permission to Quote:

We may wish to use what you said to us, the exact words, directly in reports and publications resulting from this. Please let us know if we can do that by checking yes or no for each of the following sentences:

Researchers may publish documents that contain quotations by me under the following conditions:	
☐ Yes ☐ No	I agree to have my words (typed out), and a made-up name will be used instead of my own. Example – If your name is Richard, a made-up name like Mick, would be used instead.
Researchers may publish your ecomap that consists of any words, images under the following conditions:	
☐ Yes ☐ No	I agree to have my ecomap used and a made-up name will be used for me and for any other people I may use in my eco-map. Example – If your name is Richard, a made-up name like Mick would be used and your friend Sam would have a made-up name like Pat.

Do you have to be in the study?

You do not have to be in the study. No one will be mad at you if you don't want to do this. If you don't want to be in this study, just say so. We will also ask your parents if they would like you to be in the study. Even if your parents want you to be in the study you can still say no. And even if you say yes now, you can change your mind later. It is up to you. Please let Ms. Buduhan or Dr. Woodgate know if you change your mind at any time.

Questions

If any questions come up during or after the study contact the principal investigator, Ms. Buduhan at [redacted] or [redacted]. You may also contact Dr. Roberta Woodgate at [redacted] or email at [redacted]

Assent Signatures:

I have had a chance to ask questions and get answers. I want to take part in this study. I know I can change my mind at any time.

Verbal assent given for the interview: Yes ☐ No ☐

Written assent if the participant chooses to sign:

Participant printed name: _____

Date _____
(day/month/year)

Participant signature: _____

-----*Principal Investigator Signs Below*-----

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their assent

Printed Name: _____

Date _____
(day/month/year)

Signature: _____

-----*Principal Investigator Signs Above*-----

If you would like, at the end of the study a summary will be provided by about December 2025.

I would like to have a copy of the summary of the project:

Yes

☐

No

☐

Mailing Address: _____

Email Address: _____

Appendix O

Resource List



Food Allergy in Schools Resource List for Parents and Youth

Food Allergy Education and Support

- Food Allergy Canada: <https://foodallergycanada.ca/>
- Find a dietician in Canada: https://members.dietitians.ca/DCMember/s/find-dietitian?language=en_US

Mental Health Education and Support

- Anxiety Canada: <https://www.anxietycanada.com/>
- Find a psychologist in Canada: <https://cpa.ca/public/findingapsychologist/>
- Webinar for Kids with Allergies and Anxiety:
https://www.youtube.com/watch?v=QC7EJGtL_70
- Kids Help Phone: <https://kidshelpphone.ca/>
 - Call 1-800-668-6868 (24/7) or text to **CONNECT** at 686868

Wellness Together Canada

To connect with a mental health professional one-on-one:

- Call 1-888-668-6810 or text WELLNESS to 686868 for **youth**
- Call 1-866-585-0445 or text WELLNESS to 741741 for **adults**

Appendix P

Protocol Approval



University
of Manitoba

Research Ethics and Compliance

Human Ethics - Fort Garry
208-194 Dafoe Road
Winnipeg, MB R3T 2N2
T: 204 474 8872
humanethics@umanitoba.ca

PROTOCOL APPROVAL

Effective: February 14, 2024

Expiry: February 13, 2025

Principal Investigator: Vanessa Helaine Buduhan
 Advisor(s): Roberta Woodgate
 Protocol Number: HE2024-0025
 Protocol Title: *A Hermeneutic Phenomenological Inquiry of the Lived Experiences of Food Allergy within the School Environment: Perspectives from Youth and Parents*

Hai Luo, Chair, REB1

Research Ethics Board 1 has reviewed and approved the above research. The Human Ethics Office (HEO) is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*- TCPS 2 (2022).

This approval is subject to the following conditions:

- i. Approval is granted for the research and purposes described in the protocol only.
- ii. Any changes to the protocol or research materials must be approved by the HEO before implementation.
- iii. Any deviations to the research or adverse events must be reported to the HEO immediately through an REB Event.
- iv. This approval is valid for one year only. A Renewal Request must be submitted and approved prior to the above expiry date.
- v. A Protocol Closure must be submitted to the HEO when the research is complete or if the research is terminated.
- vi. The University of Manitoba may request to audit your research documentation to confirm compliance with this approved protocol, and with the UM *Ethics of Research Involving Humans* [Ethics of Research Involving Humans](#) policies and procedures.

Appendix Q

Protocol Amendment Approval



University
of Manitoba

Research Ethics and Compliance

Human Ethics - Fort Garry
208-194 Dafoe Road
Winnipeg, MB R3T 2N2
T: 204 474 8872
humanethics@umanitoba.ca

AMENDMENT APPROVAL

April 15, 2024

Principal Investigator: Vanessa Buduhan
Advisor(s): Roberta Woodgate
Protocol Number: HE2024-0025
Protocol Title: *A Hermeneutic Phenomenological Inquiry of the Lived Experiences of Food Allergy within the School Environment: Perspectives from Youth and Parents*

Hai Luo, Chair, REB1

Research Ethics Board 1 has reviewed and approved your Amendment Request submitted on April 9, 2024, to the above-noted protocol. The Human Ethics Office (HEO) is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*- TCPS 2 (2022).

This approval is subject to the following conditions:

- i. Approval is granted for this amendment only.
- ii. Any further changes to the protocol require subsequent amendment approvals from the HEO before implementation.
- iii. Any deviations to the research or adverse events must be reported to the HEO immediately through an REB Event.
- iv. Amendment Approvals do not change the protocol expiry date. Please refer to the original Protocol Approval or subsequent Renewal Approvals for the protocol expiry date.