A CASE STUDY:

THE SCHOOL EXPERIENCES OF CHILDREN WITH LIFE-THREATENING FOOD-INDUCED ALLERGIES AND ANAPHYLAXIS AS PERCEIVED BY CHILDREN, PARENTS, TEACHERS, AND A SCHOOL ADMINISTRATOR

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Abstract

The purpose of my qualitative case study research was to examine the perceptions of children/teens, parents, teachers, and administrators around the school experiences of students with life-threatening food-induced allergies and anaphylaxis. In addition, I wondered how participants' lived experiences might serve to ameliorate educational policies and practices in schools so that all students who have food allergies and anaphylaxis can feel safe, cared for, and be available for learning. Using a purposive sample of convenience, 10 participants (including 3 children/teens, 4 parents, 2 teachers, and 1 administrator), were invited and agreed to participate in audio-recorded in-depth individual interviews around my study topic. My interpretation and analysis of interview data depicted complex connections between and among the following themes: allergy identity, safe-care strategies, labels and labelling, allergy communications, and ethical disconnects. Three recurring subthemes-time, trust, and transition, also emerged and are threaded throughout. At times, intense emotions punctuate the discourse as empathetic signposts for the reader. I conclude the study with suggestions for families and school communities so all might better support the physical, social, emotional, and academic needs of those living with life-threatening food allergies and anaphylaxis.

> "Allergy sufferers have special powers of perception." ~ Gregg Mitman

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CHAPTER ONE: INTRODUCTION TO THE STUDY

In Chapter One I begin by providing a brief overview of my research study around the school experiences of children/teens with life-threatening food-induced allergies and anaphylaxis. I have included immediately, for the reader, a discussion of the more significant terms I will use in the dissertation, as I feel a common understanding of the medical terminology is essential. Specifically, I provide for the reader a discussion of five major allergy-related terms and explain three terminology choices I have made with respect to my study. Additionally, I direct the reader to Appendix G for an extended alphabetical listing of minor allergy-related and medical terms. Next, I share a personal account of some of my experiences as the parent of two children—one of whom has life-threatening food-induced allergies and anaphylaxis. As my daughter is a central figure in my personal context, with her permission, I make public these private details in the hope they will in some small way resonate with the reader—either by promoting greater awareness, understanding, and empathy or by creating an ethical call to action as increasingly more individuals and families in our schools and communities are affected by severe food allergies. I continue by sharing my study purpose and my two overarching research questions so the reader can appreciate my interest in the study topic and have knowledge of my research intentions. Moving from the specific to the general, I provide a rationale for my research study, positioning it within a larger, more global perspective that calls attention to the increase in allergic disease and the likelihood that educators will encounter, in their classrooms, a student who has life-threatening food-induced allergies and anaphylaxis. I close Chapter One by offering the reader a preview of the forthcoming study chapters, and I highlight the organization of the document in brief.

1

Study Overview

Through the lens of children/teens with food allergies, parents, teachers, and administrators, my qualitative research study will centre around *"how"* the "social experience" of being a student with life-threatening food-induced allergies and anaphylaxis "is created and given meaning" (Denzin & Lincoln, 2005, p. 10). In my view, individual reflections on and constructions of meaning will collectively generate new knowledge (Amulya, 2011; Doll, 1993; Schön, 1992) to guide purposeful action (Mezirow, 1990; Molz & Edwards, 2013) and may result in "transformative" learning (Mezirow, 1990; see also Marlowe & Page, 1998). Working in the best interests of the student, I anticipate that my study may deepen awareness and facilitate action to inform current educational policies and procedures in schools which could, in turn, improve the physical, social, emotional, and cognitive school experiences of students with food allergies and anaphylaxis (Shapiro & Stefkovich, 2005; Stefkovich, 2006; Stefkovich & Begley, 2007).

Definition of Terms

I have positioned key terminology here in Chapter One, ahead of the study details and my personal context, as I feel that the underlying medical nature of both my study and my story requires the reader to be familiar with my understanding of terms as I will use them in the dissertation. For clarity purposes, I have organized the terminology into two subsections— *Major Terms* and *Linguistic Choices*. The five major terms that provide contextual information are organized in order of importance to my study topic. The three linguistic choices I have made are explained moving from broad collective identifiers to more specific individual ones. Also included, for ease of use and future reference by the reader, is an alphabetized list of minor allergy-related medical terms that address a number of aspects in my study (see *Appendix G*).

Major Terms

In this section, for the purposes of my study, I share five allergy-related terms, and my understanding of them, which are central to my research around the school experiences of children/teens with life-threatening food allergies and anaphylaxis.

Allergy. In its simplest form, an allergy is a chronic condition that involves an abnormal reaction to an ordinarily harmless substance (American Academy of Allergy, Asthma, and Immunology, 2015; see also Sicherer, 2013) which results in the immune system's production of antibodies that attack the substance (DeVoe, 2008). Allergy commonly manifests as asthma, allergic rhinitis, dermatitis, and/or food allergies (Rosello & Huete, 2015).

Food allergy. A food allergy is an abnormal immune system response to the proteins in foods. The immune system fights the allergic proteins by releasing chemicals such as histamines into the bloodstream and by producing immunoglobulin E antibodies (Garcia-Careaga & Kerner, 2005; Robinson & Ficca, 2012; Sabra et al., 2003; Sicherer, 2013).

Priority food allergen. In conjunction with allergy associations and the medical community, Health Canada has identified 11 proteins that are most often associated with food allergy reactions. Recognized under the Food and Drug Regulations Act, the priority allergens include: nuts (almonds, Brazil nuts, cashews, hazelnuts, macadamia nuts, pecans, pine nuts, pistachios, or walnuts), peanuts, sesame seeds, wheat, eggs, milk, soybeans, crustaceans, shellfish, fish, and mustard (Government of Canada, 2015; see also Gold, Atkinson, Lavi, & Hummel, 2003).

Anaphylaxis. Anaphylaxis is a "severe, potentially fatal, systemic allergic reaction that occurs suddenly after contact" with an allergen (Järvinen, Sicherer, Sampson, & Nowak-Wegrzyn, 2008, p. 133). Allergens that may initiate anaphylaxis include food, medications,

insect stings, latex (American Academy of Allergy, Asthma and Immunology, 2015), and physical exercise (Wade, Liang, & Sheffer, 1989).

Epinephrine. A synthetic drug form of the human adrenaline hormone that is injected to treat life-threatening allergic reactions to food, medications, insect stings, and latex (American Academy of Allergy, Asthma, and Immunology, 2015; Anaphylaxis Canada, 2015). Currently, epinephrine is the first line treatment for anaphylaxis (Canadian Society of Allergy and Clinical Immunology, 2014; Douglas, Sukenick, Andrade, & Brown, 1994; Järvinen et al., 2008).

Linguistic Choices

In this section I explain three purposeful linguistic choices I have made and reveal my thinking about how the language of allergy labelling can be helpful or harmful.

Severe food allergy. For the purpose of my study, I have defined *severe food allergy* as any food allergy that has been determined by a physician to have the potential to result in an anaphylactic reaction requiring a medical prescription for the potentially life-sustaining drug epinephrine (Brown, 2004; Tan, Sher, Good, & Bahna, 2001). Further support for my choice is found in both qualitative and quantitative allergy literature (Brown, 2004; Graceffo, 2008; Hay, Harper & Moore, 2006; Robinson & Ficca, 2012; Rouf, White, & Evans, 2011; Tan et al., 2001).

Child(ren) with food allergies versus *food-allergic child(ren)*. I have decided to use the nomenclature *child(ren)* with food allergies instead of *food-allergic child(ren)* in my study. It is my view that if "language and cultural patterns have a reciprocal relationship" (Parks & Roberton, 2004, p. 238), then positioning *allergy* before *child(ren)* in *food-allergic child(ren)* suggests the primacy of the allergy over the individual, which may stigmatize (Monteath & Cooper, 1997). Positioning child(ren) first acknowledges allergy is only one aspect of an individual's identity.

Child/ren versus *student*. Study participants who are under age 18 are first *children*, and for the purpose of my work will be referred to as such, although I may use *teen* to describe teenage participants. Since my research aims to address the *school* experiences of children with food allergies, I may use *student* as the education-related identifier as applicable.

Introduction: My Context

In this section, I detail some of my experiences as the mother of a now 16-year-old who has been dealing with life-threatening food-induced allergies since birth. As my daughter is a central figure in my personal context, with her permission, I share select private details in the hope that our lived experiences will in some way make an impression on the reader and/or those who find themselves in like circumstances. I share the initial manifestations of food allergy in my breast-fed infant, her exposure to new food items, my search for a diagnosis, the relationship between food allergies and other atopic diseases, as well as transitions from home to elementary and secondary schools.

Consumed

In a bedside table in my room, I keep a red duotang. I rarely look at it now, but from the September day I brought my newborn daughter home from the hospital to February of the following year, this simple book was my lifeline. A carryover from the first few days of life in the hospital, the red duotang holds the required record keeping of the input and output of a newborn baby: dates, times, breast-feeding schedule, a description of the colour and texture of my baby's bowel movements. Unpleasant when I think about it now, but at the time I had no idea what I was doing and was trying to be a good first-time mom, following the nurses' advice. Time disappeared—*thedaysbledintooneanotherasonlyasleepdeprivedparentcouldknow*. The only thing delineating days from nights was the occasional entry in my duotang by my husband

indicating "a.m." or "p.m." beside the breast-feeding schedule. Left-right-left-right-left-right— I nourished my child with military precision: times accurate to the minute. Ironically, I did not know at the time that my life-sustaining milk supply might be linked to a bigger problem.

Something changed on October 5—the first time I saw blood in my daughter's diaper. Looking at the entry now I read "**bloody?**" noting a question mark; perhaps mocking, doubtful, not really trusting what I know I clearly saw (Personal Journal, 2000). We were told our daughter had likely contracted the rotavirus at her well-baby check-up the week prior and that troubles should resolve in a few days. When symptoms worsened, one of the many hospital doctors we saw told my husband and me that our daughter could have Hirschsprung's disease. I didn't know what that potential diagnosis meant but abruptly understood when a possible worstcase scenario was explained that involved our daughter going to Sick Kids Hospital in Toronto to have part of her bowel removed. I had forgotten about the temporary Hirschprung's diagnosis, but memories came rushing back after finding a hastily printed article from the internet secured in the back of my duotang. I was desperate to make sense of my potential newfound reality, grasping at anything that might bring clarity, my "old ways of knowing" no longer making sense (Mezirow, 1990, p. 14). My daughter did not have Hirshsprung's.

The cause of my daughter's health concern, as someone had suggested, didn't seem to be gastroesophageal reflux either—the classic oversupply of milk, fussiness when feeding, persistent burping, and projectile vomiting were not symptoms we encountered. What my daughter did experience was acute pain and exhaustive crying, especially in the evenings after a day of recommended regular feedings to prevent dehydration and ensure weight gain. The crying seemed to be relieved only by bloody stool elimination. Experienced mothers suggested infant colic, which seemed to make sense; daily bouts of nonstop crying with rigid legs extended in pain, with no outward signs of illness, and regular feedings resulting in consistent weight gain. I proceeded on the premise that the blood was a result of the rotavirus having attacked my newborn's gastrointestinal tract and that it lingered because some areas had not yet healed. I heeded advice from mothers, grandmothers, and aunts and began trying anything and everything to calm my distressed child. My husband and I raised the head of her mattress (just in case it really might be reflux). We kept to a regular daily life schedule and tried to avoid overstimulating our daughter. My husband tried the *colic carry*, laying our baby's abdomen on his forearm with her legs astride his elbow in an attempt to ease pain and even ran the vacuum to provide white noise as someone had suggested. We hoped that 150 years of anecdotal evidence suggesting that gripe water alleviates gastrointestinal discomfort would help. To this day, the word "gripe" floods my sensory memory with the taste and smell of the licorice-flavoured, fennel oil-containing product. Intuitively, as a mother, I felt something still was not right.

I notice now that my duotang record-keeping began to change at this time. In addition to feeding times and descriptive diaper contents, I notice other words like "mucous," and "Ovol® drops" interspersed throughout (Personal Journal, 2000). Following medical advice, we gave our daughter Tri-Vi-Sol®, a supplement containing vitamins A, C, and D designed to support immune system development in breast-fed infants. I can't help but wonder now if immune system development would be better or worse had we not tried Tri-Vi-Sol®, or breast-feeding for that matter. I seemed to have recorded anything that might be a clue to my daughter's curious condition. I see "Dr.'s office – 8 lbs, 10 oz," "36.2°C," "5 cc," "alert," and "fell asleep quickly" (Personal Journal, 2000). On October 13th (ironically a Friday, I've determined), I note that I began, as medically advised, to track my own food intake, as "milk protein intolerance" (a name I hastily scribbled on the last page in the duotang, recorded for a future internet search)

was now suspect. I had already reduced my intake of gassy foods like cauliflower, broccoli, garlic, and onions to see if doing so would help with the evening colic symptoms. Although I learned that Friday of a connection between eczema, rhinitis, and milk allergies, I recall feeling skeptical of the milk protein intolerance diagnosis since at that point I hadn't had milk in almost 14 years and wasn't exactly sure how that protein was reaching my daughter. In my concerned state, I didn't immediately think about other ways milk protein could be getting into my system. I didn't think to ask about how an allergy works either—I was too busy digesting the information that my daughter's cradle cap and hardened nasal mucous was somehow connected to her crying, stomach pain, bloodied diapers, and my diet. I accepted an appointment to learn about milk protein allergy, foods that "may contain" milk, and protein words like "casein" and "whey" (highlighted on two milk-alert wallet-sized allergy cards). I left with the name of a cookbook that I should purchase (Eating Well, Milk Free: A Cookbook and Guide by Christine Wellington) and the phone number of a local woman who was willing to speak with *recently diagnosed* milk allergy patients. Determined, I bought the book and made the call. Knowing that everything I ate would eventually be passed onto my daughter through breast milk, I had officially embodied allergy but was not allergic.

Our symbiotic relationship continued: my baby gaining weight and me losing it as I began a maternal elimination diet to determine if what I was eating could be the cause of her internal distress. Overnight I had become an avid food label reader as I worked to remove any possible milk protein from my diet. As had been medically suggested, I avoided: cheese, cheese flavourings, sour cream, dips, butter, as well as any product containing milk solids, milk powders, whey, casein, lactoglobulin, and protein hydrolysates (just to name a few of my newly assigned signal words). When there was no difference in my daughter's symptoms, I obediently continued with the elimination diet, gradually working my way down the provided list, eventually excluding: spicy foods, acidic foods, tomatoes, citrus, fruit, fats, and oils to see if I could target the responsible food item as I became more and more convinced milk wasn't the culprit. Meal preparation became challenging and food more bland every day. Not knowing if what I was consuming could potentially harm my child, eating was no longer an enjoyable part of my family's day. I quickly lost the 12 pounds I had gained when pregnant, and an additional 48 melted from my frame.

For a short while, from October 16th to the 20th, my lined paper annotations switched to a computer generated template my dad had created for me, complete with the subheadings "date," "time," "diaper condition," and "other" (Personal Journal, 2000). "Diaper condition" was a neutral name I'm sure my dad selected to soften the emotional blow I felt each time I changed a bloodied diaper. While I know his intent was to be helpful, I rejected the idea of the organizational template, feeling as if I accepted the order of it then I would be accepting that this bloody reality would persist. I pressed on, desperate to uncover what was wrong with my child as I became increasingly convinced that milk protein was not the cause. Late October notes included more medical terminology: "blood work," "gastroenterologist," "radiology," "barium follow up picture," and the recorded weights of measured wet diapers "before 4.685 kg; after 4.800 kg" (Personal Journal, 2000). November annotations became more detailed: "bloody mucous," "some blood," "bright red," "runny," "smelly," "lots of blood," "blood clot," "huge blood clot," "ALL BLOOD" (Personal Journal, 2000). Sometimes I tallied the number of bloody stools at the end of the day, hopeful that it would somehow make a difference at one of our three weekly medical specialist appointments: "12 poops (11 with blood), 10 pees," or "7 poops (6

with blood)" (Personal Journal, 2000). No explanation for years. I had a healthy baby who was feeding well and gaining weight—just don't open the diaper.

Oddly enough, I thought I stopped tracking in February of 2001, the day after a family birthday celebration and Ashley's worst diaper ever—I had had enough. I see now that December 16th was my last entry. Both of my supportive parents' handwriting is alongside mine on the last page. Did I record past this date? Where are my notes? There are still empty lined pages; why did I seem to stop? Did I throw them away? An unfilled prescription for Nutramigen® (a predigested baby formula) is wedged between the pages at the back of the duotang—my insistence that I not formula feed while Ashley was sick. I noticed a ripped copy of "The Canadian Memory Capsule 2000–2001," a pamphlet insert put out by *Maclean's* magazine stored at the front of the duotang. Perhaps it was a reminder of all of the events that were taking place in Canada during this time when I was otherwise occupied.

Introducing Food

At 5 and a half months old, I began to introduce solid food into Ashley's diet. Since our daughter had atopic tendencies, medical advice advocated for a slow integration of food into Ashley's diet to ensure a physical response could more readily be attributed to a particular product. In keeping with the thinking of the time (American Academy of Pediatrics, 2000; Bergmann, Wahn, & Bergmann, 1997), doctors advised my husband and me to wait until Ashley was at least 3 years old to try some of the commonly known childhood allergens such as peanut butter and fish. Strawberries can cause hives in some children, so we avoided those as well. We complied for over 2 years, slowly adding new food items, including milk products to our daughter's diet, with minimal negative response. Interestingly, ketchup and cantaloupe were the only products to elicit any kind of reaction (and inconsistent at that): an occasional small contact

rash on the side of Ashley's mouth that lasted roughly 30 minutes, then disappeared. Since she seemed to enjoy these foods, we continued to offer them to her and cautiously observed, waiting. No negative response ensued, so we carried on with our lives; cautiously optimistic but ever vigilant.

"My Ears Are Closing"

As advised, we waited until Ashley was 3 years old before introducing some of the priority allergens into her diet. At 3, Ashley already had no trouble with eggs, milk, soy, or wheat products (and still enjoys these foods today). The first time Ashley tried peanut butter was at home on a soda cracker. After one bite, she had an immediate physical response and her normal demeanor changed instantly. She spat the cracker out and began scraping her tongue with her fingers. She was clear that she did not like peanut butter, telling us it tasted like a tin can (how she knew what a tin can tasted like, I didn't know). We weren't sure if Ashley didn't like the taste or the texture of the peanut butter or if there was something more. To be honest, we really had no idea what we should have been looking for in an allergic reaction and naively did not realize her response was as serious as it turned out to be. We were sure we would not give Ashley peanut butter again without first seeking medical advice. Wanting to know before she began school, I gave Ashley one small bite of a peanut butter square—again, an immediate physical reaction and behaviour change. Ashley tried to scratch her tongue and clear her throat while yelling "my ears are closing" as I tried to get Benadryl® into her. That second home trial, now 13 years ago, was the last time we knowingly fed our daughter a product containing nuts.

Allergies, Asthma, and Eczema

When Ashley entered junior kindergarten in the fall of 2004, we still did not have an official medical diagnosis of food allergy, though intuitively, as a mother, I knew, and we worked to avoid contact with nut products. At the time I felt nut avoidance was somewhat

manageable at school because educators worked to ensure the safety of other children with nut allergies who were in the building. Memos provided tips on how to pack safe lunches, notes were sent home with unopened items that contained nuts, and students were taught how to keep their peers safe.

We went through a period of about six months that year where new symptoms appeared. Ashley would cough every night for about an hour as she attempted to fall asleep. The coughing would stop only after she vomited up her dinner and a significant amount of mucous, each night collapsing in exhaustion. We were told that Ashley had asthma and she was subsequently sent for lung function tests that confirmed the diagnosis. Exposure to irritants like smoke, fumes, or inhaled allergens, as well as extreme cold temperatures or respiratory viruses aggravated Ashley's lungs. The following summer, dry, itchy, red patches of skin, reminiscent of the cradle cap she had as a baby, began to appear behind Ashley's knees and on her elbows—eczema. The allergic march had advanced and we soldiered on. In May of 2007, with the number of atopic conditions continuing to increase, Ashley was finally prescribed an EpiPen® for emergency use.

Elementary School: An Excerpt from My Personal Journal

As a parent and an educator, the thought of sending my daughter to school each day is frightening. It's not so much packing the nut-free lunch or ensuring that Ashley's EpiPen® is in her backpack but rather the fear of the unknown and the unpredictability of the behaviour of others that concerns me most. It's sometimes difficult to trust that people *really* know, understand, or care that sending my child to school each day may be a life-threatening risk. Although I have filled out the necessary forms for the bus consortium, informed Ashley's teachers of her medical needs, and met to provide school administrators with a completed anaphylaxis plan and the accompanying medication, I still worry. I think about the children who travel on the bus with Ashley. I wonder if her

peers who have had peanut butter or Nutella® on toast that morning have washed their hands and brushed their teeth before leaving home. I hope that she will not be teased or tested by her friends. I wonder about the parents of the other students—are they frustrated every time they pack a lunch for their children; do they make a concerted effort to be *nut-free* so that my child and others like her can have the experience of attending a public school safely. I worry about the lack of adult supervision of individual classrooms during the lunch hour. I question whether or not the grade 6 students lunch monitoring the primary classrooms would be able to recognize the signs of anaphylaxis, get help from a teacher, or, if needed, administer a potentially life-saving injection of epinephrine within the critical first minutes of an anaphylactic reaction. Furthermore, despite the best efforts of everyone else, I am concerned that Ashley may make the decision to share a snack from someone else's lunch without first reading a food label—a huge responsibility to place on a young child but one that I as her parent must help her navigate. (Personal Journal, 2008)

Transition

From ages 8 to 13 Ashley's food issues intensified. In addition to avoiding all nuts, it seemed many raw fruits and vegetables caused oropharyngeal reactions. We didn't really understand the complexity of allergy, so we tried organic foods to see if there was a difference. We tried cooking apples, strawberries, and carrots to see what would happen—results were inconsistent. There did not seem to be any pattern regarding what Ashley would respond to. Her reactions involved itchy lips, tongue, mouth, or throat and seemed to be brought on by: apples, carrots, celery, kiwi, strawberries, raspberries, blueberries, cherries, peaches, nectarines, plums, grapes, cucumbers, honeydew melon, watermelon, and eventually bananas. Oranges and pineapples were the only fruit items Ashley tolerated for a few years. At age 8, positive RAST

tests confirmed peanut and cashew had *moderate* allergic responses, and hazelnut scored *high* for Ashley. Since at that point fruits or vegetables were not positive, we were told Ashley had oral allergy syndrome.

A "Big" One

A few weeks before Ashley's 10th birthday, our extended family was enjoying a meal together at my parents' home. As had become our meal preparation routine, my mom saved all of the ingredient labels for any prepared foods that were being served. Although we checked the food labels, we went through a double-check process every time. I don't recall the meal's main course, but I do recall hesitating when reading the ingredient list on a prepackaged specialty cake imported from Italy that was to be a part of the dessert course. I should have trusted my hesitation. The reaction that ensued was not what I had expected an anaphylactic reaction to be. Immediately after dessert, Ashley complained of a tight throat— by now a familiar symptom of the oral allergy syndrome she frequently experienced. We gave Ashley Benadryl® and shortly thereafter, when she was staring straight ahead of her, seemingly out of it, we left for home. While it was an awful feeling seeing my daughter like this, at that point I still did not realize her symptoms were as serious as they were-I was waiting for the high-pitched wheezing sound called stridor as evidence of an obstructed airway and my cue to administer epinephrine. When we arrived at the hospital we learned that the breathing trouble in combination with Ashley's altered state of consciousness and previously unnoticed hives that covered the core of her body indicated she was having an anaphylactic response. Subsequent research to determine the cause of Ashley's reaction led me to believe that the ingredient *flavouring* was the culprit, as I learned that both hazelnut and almond are two common flavours used in Italian baked goods.

While the reaction was traumatic for Ashley and our family, what followed in the weeks to come was just as troubling; Ashley lost 25 pounds in very short order brought on by her fear

of consuming an unknown allergen. In an attempt to allay her concerns about eating, meal preparation focused on family favourites made with trusted brands. We scrutinized food labels at the time of purchase, prior to cooking, and had a joint reading just before we sat down as a family to eat. For about six months, a three-check-mark strategy we devised provided an extra sense of food safety and security if prepackaged items replaced homemade ones in school lunch pails. We normalized this new reality and shared responsibility for Ashley's health until she was once again able to independently negotiate the tension she felt each time she ate.

The List Goes On . . .

Things started to make more sense to me once Ashley had aeroallergen skin prick tests done at age 10 revealing high level reactions to (in descending order): birch, oak, tree mix, grass mix, ragweed, willow, and ironically *ash* trees. An internet search of *cross-reactivity* was a *light bulb* moment for me because every fruit, vegetable, or nut that Ashley reacted to was linked to an aeroallergen. For example, birch tree pollen, Ashley's most responsive test result, is cross-reactive with hazelnut, her most severe nut allergy. As well, apples, carrots, celery, kiwi, peaches, nectarines, and cherries, which are some of Ashley's oral allergy syndrome foods, are also connected to birch pollen. I cringed when I saw fennel on a list of food allergens linked to birch. The pieces of my daughter's allergy puzzle were finally starting to fit together.

On the Move

Ashley's transition from grade 6 to grade 7 involved a move from the elementary school to the high school building where the intermediate program was situated. The physical space, although located within the secondary school, was very much managed as the nearby elementary school had been: The students had their own entrance, they ate lunch in their classrooms, and with the exception of music and physical education classes, they stayed in the intermediate wing. For Ashley it was an exciting time but not one without challenges. A new school meant new

students from other schools, many of whom did not know about Ashley's allergies. Once again, a preteen girl's nightmare, to be made the centre of attention in class, even for a brief moment, for an issue that seemed to be a very private one. Unfortunately, the reminder to peers also increased her vulnerability as we soon found Ashley was being teased about her allergies by a classmate. Despite in-class discussions, the high school students who rode the same bus did not know of Ashley's allergies and on two occasions, one day apart, a jar of peanut butter and a jar of Nutella® were opened and eaten on the bus. Ashley's hypersensitive olfactory system kicked into high gear and so did her friends, alerting the driver of the danger. Self-advocacy worked for Ashley most of the time, but she admits that not all students really seemed to understand the concept of a life-threatening allergy; "why would they," she says, "they don't live it."

Grade 9 brought more risk and responsibility as Ashley moved from the intermediate to the secondary wing of the school. She found navigating new learning spaces to be difficult at times. The fumes from the required shop classes would irritate her lungs and cause coughing fits, physical education classes held outdoors at the height of allergy season made for itchy eyes and a runny nose, and finding a safe place to eat lunch with friends (not in the cafeteria) proved challenging. It seems to me to be less acceptable to monitor food consumption in a nut-safe high school than in an elementary setting. I also feel there exists a perception that teenagers can handle the responsibility for their own food allergies on their own; however when the rules and structures put in place to keep students safe are not adhered to by others, it becomes harder for teens to self-advocate, especially with the social dynamics of a secondary school at play.

Currently

My daughter Ashley, now 16 as I write my context for my dissertation, has just undergone her second round of 42 skin prick tests (some prepared serums and some with whole foods items we brought to the appointment). We are fortunate there is now a pediatric allergy clinic closer to home that is open 4 days a year and we no longer have to drive 4 hours for testing. New this time, pistachios, almonds, walnuts, apples, pears, strawberries, and cherries had positive reactive results. Mugwort and weed mix responded as well. Confirmatory blood tests are pending but, with medical approval, Ashley can *cautiously* try some of the fruit items that had previously caused issues. We worked backwards, reintroducing food items that had last caused a reaction. Ashley can, once again eat bananas, watermelon, cucumbers, and honeydew melon. She has also tried coconut flakes, avocado, and sunflower seeds for the first time. Ashley remarked, "I feel like I have a whole new world of food opportunity opening up to me."

Purpose

The purpose of my study is twofold: (a) to create a *rich* (Denzin & Lincoln, 2005; Merriam, 2009) or *thick* (Glesne, 2011; Patton, 2002) description of the school experiences of children with severe food allergies and anaphylaxis from the perspectives of parents, school administrators, teachers, and the children with food allergies themselves; and (b) to engage study participants in a generative process of sharing insights and suggestions in order to improve the physical, social, emotional, and cognitive school experiences of these children and perhaps others with life-threatening food-induced allergies and anaphylaxis (Doll, 1993). I anticipate that individual research participant contributions may help, in some small way, to inform the collective understanding of the everyday experiences of children affected by food allergies and anaphylaxis (Denzin & Lincoln, 2005), and it may also assist readers of this work who make ethical decisions in the best interests of children attending schools (Shapiro & Stefkovich, 2005).

Research Questions

Two overarching "generative" research questions will frame my study and help guide my inquiry (Agee, 2009):

 What are the school experiences of children with severe food allergies as perceived by parents, school administrators, teachers, and the children themselves?
How might the experiences of the study participants inform educational policies and procedures in schools in order to ameliorate current processes that might better ensure safe and sustainable practices and learning environments for all students with food-induced allergies and anaphylaxis?

It is my view that study participants' responses will inform my first research question by providing an understanding of the study phenomena and will signal the relevance of my second research question (Agee, 2009; Patton, 2002) within the fields of education, leadership, ethics, values, sustainability, and possibly medicine, psychology, sociology, and law.

Rationale for the Study

In the last 2 decades, there has been a significant increase in the incidence of children with severe food allergies (George & McQuaid, 2010; Gruchalla & Sampson, 2015; Hay et al., 2006; McIntyre, Sheetz, Carroll, & Young, 2005; H. Sampson, 2003; Shemesh et al., 2013). The unexpected rapid growth and global expansion of food allergies has resulted in researchers referring to the proliferation as an *epidemic* or widespread occurrence (Sicherer & Sampson, 2007; Velasquez-Manoff, 2012). Approximately one quarter of children in Canada are troubled by an allergic disorder (Gold et al., 2003), only one third of which are related to food allergies (Shemesh et al., 2013), with the top 11 priority allergens being: peanut, tree nut, egg, milk, soy, wheat, fish, crustaceans, sesame, sulfites (Gold et al., 2003), and newest addition, mustard (Government of Canada, 2015). Since there is currently no known cure for food allergies (Anagnostou et al., 2015; Crain, 2011; Greenhawt, 2014; Oppenheimer, Nelson, Bock, Christensen, & Leung, 1992; Sicherer, 2013), parents of children with life-threatening food-

induced allergies and anaphylaxis are responsible for helping their children accept, manage, and live within the restrictive boundaries the allergies impose.

Food allergies are most often diagnosed by a physician only *after* an exposure and reaction to an offending allergen, with fatal food-induced anaphylaxis more commonly affecting "adolescents" and "young adults" at restaurants or school (George & McQuaid, 2010; see also Hay et al., 2006; McIntyre et al., 2005; Sheetz et al., 2004). Sadly, the most "critical" factor associated with death due to food-induced anaphylaxis has been the delayed administration of epinephrine (Canadian Society of Allergy and Clinical Immunology, 2014; Frew, 2011; Hay et al., 2006; McIntyre et al., 2005; Powers, Bergren & Finnegan, 2007; M. Sampson, Muñoz-Furlong, & Sicherer, 2006). Providing "safe care" for students affected by food allergies and anaphylaxis is becoming more challenging as families and school communities work to address the interconnected physical, social, emotional, and cognitive dimensions that allergies present (McIntyre et al., 2005).

As the incidence of food-induced allergies and anaphylaxis continues to rise, particularly in industrialized societies (Jackson, 2006; Rosello & Huete, 2015), there is an increased concern about educators' awareness of, and their ability to respond in an anaphylactic emergency (McIntyre et al., 2005). In addition to the physical risks, there are social implications as well. In a study out of the Jaffe Food Allergy Institute at Mount Sinai Medical Center in New York, Shemesh et al. (2013) found that 42% of children with food allergies aged 8–17 reported being teased because of their food allergies and 30% have had food waved at them. The social vulnerability of students with food allergies is apparent as 80% of food bullies were classmates (Shemesh et al., 2013). Simply knowing the signs of anaphylaxis is no longer ethically sufficient; educators have a moral responsibility to build relations of care and trust (Noddings, 2012a) so they may act in the "best interests" of all students (Shapiro & Stefkovich, 2005).

Organization of the Study

I began Chapter One by offering an overview of the study that suggested how my work may increase awareness and support informed ethical decision-making in schools in the best interests of students with severe food-induced allergies and anaphylaxis (Shapiro & Stefkovich, 2005; Stefkovich, 2006). I then provided for the reader my understanding of five major allergyrelated terms as they will be used in the study and clarified three linguistic choices I have made with respect to my research study. I also called attention to Appendix G which provides an alphabetical listing of several minor allergy-related and medical terms. Next, I shared select personal experiences and relevant notes from a personal record-keeping journal in order to contextualize for the reader, my research interests around the school experiences of children with life-threatening food-induced allergies and anaphylaxis. My study purpose, both descriptive and generative (Doll, 1993) was subsequently followed by my two overarching research questions, which serve to focus my inquiry (Agee, 2009) and situate it within a larger educational context. In the preceding section, a rationale for my research signaled the global increase in food allergy as a likely indicator that educators will encounter in their classrooms a child with food allergies and anaphylaxis and may be required to respond in an emergency situation. The following paragraphs offer a brief outline of the contents of the forthcoming chapters.

In Chapter Two, I provide a review of the relevant literature pertaining to my study topic around the school experiences of students with life-threatening food-induced allergies and anaphylaxis. In the first of four sections in the chapter, I discuss the use of the term management as it pertains to food allergy and anaphylaxis. In the second section I address physical aspects of allergy and anaphylaxis including: initial exposure, diagnosis, theories, prevalence, signs, symptoms, and treatment. I focus, in the third section, on the social and emotional characteristics of daily family life with food allergy and anaphylaxis. In the final section of the chapter, I use the "best interests of the student" model as a framework for thinking about how the ethics of justice, the profession, critique, and care shape ethical decision-making practices in schools (Shapiro & Stefkovich, 2005; Stefkovich, 2006).

In Chapter Three, I situate myself in the study before going on to explain my choice of qualitative case study using in-depth audio-recorded interviews as my primary data collection method. I share the ethical considerations to which I attended when planning and implementing my research study. I then provide my sample selection criteria and introduce my participants using reader-friendly profiles. I discuss interview settings and data collection procedures before closing the chapter with my validity highlights.

In Chapter Four, I begin by detailing my data interpretation and analysis procedures. I then present and discuss each of my five major themes around: (a) allergy identity, (b) safe-care strategies, (c) labels and labelling, (d) communicating allergy, and (e) ethical disconnects. As well, the discussion of each major theme concludes with an image (or images) that is a visual representation of the theme. Three subthemes—time, trust, and transition are threaded throughout the five thematic discussions. In addition, I insert a recurring *personal aside* to share my personal perspective.

In Chapter Five, I provide for the reader an overview of my research study, situating my findings within the extant literature. I pull together my three subthemes in order to make explicit the interrelationship between and among time, trust, and transitions. Then I highlight select ethical calls to action as pertaining to each of the four ethics of critique, justice, the profession, and care. Next, I share the importance of my study before noting the strengths and limitations

therein. I close the chapter with recommendations for future research before offering my final thoughts on my research study.

CHAPTER TWO: A REVIEW OF THE RELEVANT LITERATURE

In this chapter, I provide for the reader a review of the extant literature pertaining to the school experiences of children with life-threatening food-induced allergies and anaphylaxis. As the purpose of the literature review is to situate the reader "in the topic of interest" (Merriam, 1998, p. 58), I begin by calling attention to the word *manage* and note its pervasive use in the scientific, medical, and educational literature around food allergy and anaphylaxis. I share this signal at the beginning of the chapter so the reader may pause to "reflect-in-action" (Schön, 1983, 1987) about the meanings of manage and/or pause to consider the tension that may exist between the management of allergy and anaphylaxis in *theory* and in *practice*. I continue the review addressing three major themes, organized using the following headings: (a) Allergy and Anaphylaxis; (b) A Day in the Life: Allergy, Anaphylaxis, and the Family; and (c) Allergy and Anaphylaxis Go to School. Two recurring subtopics, **safety** and **care**, are interwoven throughout. I conclude the chapter by explaining how my research study may fit within the extant literature and offer thoughts on how it may contribute to knowledge creation.

Managing Allergy and Anaphylaxis

The underlying theme of *management* seems to me to pervade not only the medical allergy and anaphylaxis literature but the school-related allergy literature as well. As allergy is a disease with "many expressions" (Larsen, Broge, & Jacobi, 2016, p. 27; see also Kumar, Teuber, & Gershwin, 2005) and without clear boundaries (Nettleton, Woods, Burrows, & Kerr, 2009), I am attuned to the implications of the term "manage" and its derivatives, in both theory and practice. Given recent medical recommendations espousing a more active approach that includes the early introduction of "potentially allergenic foods that are tolerated," it is likely that the complexity of food allergy management will increase (Anagnostou et al., 2015, p. 386).

Allergy and Anaphylaxis

Anaphylaxis and allergy have had relatively brief but "complex" histories, made increasingly so by "constructed and reconstructed" political, social, economic, and cultural dynamics (Nettleton et al., 2009, p. 649; see also Jackson, 2006; M. Smith, 2015). The term "anaphylaxis," derived from the Greek "ana" meaning "against" and "phylaxis" meaning "protection," was first used by physiologists Charles Richet and Paul Portier in 1901 to describe a hypersensitive reaction in dogs following a second injection of an experimental vaccine (Jackson, 2006; see also Edwards, 2009).

In 1906, Austrian pediatrician Clemens von Pirquet, working in the field of immunology, introduced the term "allergy" to mean a state of "altered biological reactivity" (Jackson, 2006, p. 10; see also Edwards, 2009; Sherman 1950). At the time, there was much speculation among von Pirquet's contemporaries about the "seemingly parallel processes of immunity and hypersensitivity" (Jackson, 2006, p. 33). Allergy as "immunity" and "supersensitivity" had not previously been considered "related" (Edwards, 2009, p. 3), much less a "cause" (Jackson, 2006, p. 10; see also Edwards, 2009) of hypersensitivity as von Pirquet had suggested.

Initial Allergen Exposure

While medical and scientific communities now understand the "immunological processes associated with the antigen and the allergic body," there is not one agreed-upon explanation for the underlying *cause* of allergy, its seeming "global surge," or the apparent "shift" toward food allergy in particular (Nettleton et al., 2009, p. 651; see also Jackson, 2006; M. Smith, 2015; Velasquez-Manoff, 2012). It seems important to note that while a first exposure to any allergen *does* initiate antibody production, it rarely results in a noticeable immune system response (Psenka, 2014). It is only after a subsequent exposure that an individual becomes sensitized to

the allergen (Ring, Krämer, Schäfer, & Behrendt, 2001; Ring & Möhrenschlager, 2007). Four possible routes of initial allergen exposure will be developed in the subsections below.

Ingestion of allergens. Consumption of a food item containing an allergen is the most common way individuals are initially exposed and subsequently sensitized to a food allergen (Tan et al., 2001). Ingestion of medicines, including aspirin or penicillin, can also cause allergic reactions (Sicherer, 2013). A special ingestion risk can occur when breast-fed infants are exposed to an allergen via their mother's breast milk, which can result in eczema or mucous and blood in the stool (Sicherer, 2013). Although the allergen levels in breast milk are typically low, a lactating mother may be advised to avoid or restrict particular food items (Chandra, 2002; De Boissieu et al., 1997; Sicherer, 2013; Warner, 1980). There is evidence to show that initial allergen exposure can occur in infancy as a result of trace amounts of peanut oil in both vitamin D supplements and the lipids in infant formulas (De Montis, Gendrel, Chemillier-Truong, & Dupont, 1993; Moneret-Vautrin, Hatahet, & Kanny, 1994). Even though it is the most plausible food protein sensitization route, ingestion fails to explain the dramatic increase in food allergies, particularly peanut, over the last 20 years.

Inhalation of allergens. The inhalation hypothesis suggests that individuals can experience their first allergen exposure by breathing the allergen in. Although airborne sensitization to allergic proteins is more commonly associated with respiratory allergens such as pollen, mold, and dust, an air–food connection does exist as in the case of oral allergy syndrome (see *Appendix G*). Initial allergen exposure and eventual sensitization to food proteins can also result in atopic manifestations such as asthma or allergic rhinitis, an example being baker's asthma where ingestion of the offending food protein does not necessarily produce an allergic response, but inhalation may (Brisman, 2002; Sicherer, 2013).

Skin contact as first exposure. Initial allergen exposures can occur simply by touching the allergenic item on the skin. Some common examples of allergen exposures that occur through touch are: latex, poison ivy, or nickel (Psenka, 2014; see also Birmingham & Suresh, 1999; Lidén & Carter, 2001; Lidén, Skare, & Vahter, 2008; Suli et al., 2004). Skin contact food allergens to milk, egg, soy, wheat, peanut, fish, and tomatoes have been documented in the literature as well (Tan et al., 2001). A more precise type of contact exposure, that of "broken skin" posits that medicinal ointments containing peanut oil and marketed for relief of inflamed or eczema-prone skin could be a possible explanation for the increase in peanut allergies in particular (Lack, Fox, Northstone, & Golding, 2003; see also Weeks, 1996).

Injection of allergens. Initial allergen exposure as a result of injection is known to occur as a result of the venom from an insect sting or from medications (Sicherer, 2013). The most common insect sting allergens include those from bees, wasps, hornets, and fire ants, although allergic reaction to the stings or bites of ticks, spiders, and scorpions are recognized in allergy studies (Järvinen, 2009). Small quantities of food allergens continue to be used in vaccines and include: trace amounts of egg in influenza vaccines, egg in the yellow fever vaccine, milk in the diphtheria, pertussis, and tetanus combination booster (Sicherer, 2013; see also Gold et al., 2003), as well as pork or beef gelatin found in the measles, mumps, rubella and the varicella vaccines (Bogdanovic, Halsey, Wood, & Hamilton, 2009).

Diagnosing Food Allergy

The diagnosis of a food allergy typically occurs after an individual is exposed to and experiences symptoms caused by an offending food item (George & McQuaid, 2010). While a food allergy diagnosis should ideally be confirmed by an allergist, the reality is, however, that most people who have a food allergy are managed by non-allergists and only a fraction are

referred to specialists (Cruz, Wilson, Fiocchi, & Bahna, 2007). In addition to a complete medical history, diagnosis of a food allergy almost always includes confirmatory skin and blood tests, as will be outlined below (Hay et al., 2006).

Using medical history and food journals to help diagnose food allergy. If an individual suggests food allergy as a possible explanation of symptoms, a physician may ask for a patient history of the specific symptoms experienced in relation to a suspected food (Garcia-Careaga & Kerner, 2005). When symptoms cannot be narrowed to a suspected food item, the individual may be asked to record all food and drink items that have been consumed as well as any symptoms experienced over the course of 2 weeks (Bahna, 2003b; Bindslev-Jensen, 1998). As well, any additional factors such as how the food was prepared, food item quantity, exercise, ingestion of aspirin, or alcohol consumption are helpful in diagnosis (Burks et al., 2012).

Physical examinations to help diagnose food allergy. If an individual is experiencing the symptoms of a suspected food allergy when s/he sees the physician, the doctor will take a medical history, assess, and treat symptoms as required. The physical exam may include a discussion of other possible non-allergy causes of the symptoms and may be followed by physician-ordered confirmatory blood tests (Bahna, 2003b).

Elimination diets to determine trigger allergens. An elimination diet requires the avoidance of a suspected food item for a period of at least 2 weeks to determine if there is a change in symptoms (Gold et al., 2003). Some physicians may suggest a food journal to record consumption of food and drink items and symptoms in order to more accurately provide a diagnosis. In the case of an exclusively breast-fed infant who is thought to have a food allergy, the physician may ask a breast-feeding mother to remove a suspected offending food item from her diet, as babies can become sensitized to the proteins in foods ingested by the mother (Cant,

Marsden, & Kilshaw, 1985; Cantani, Ragno, & Businco, 1992). Specifically, beta-lactoglobulin, casein, ovalbumin, gliadin, and peanut have been detected in the milk of lactating mothers (Cantani et al., 1992; Gold et al., 2003) with hen's egg ovalbumin and cow's milk protein appearing between 2 and 4 hours after consumption (Cant et al., 1985). If the infant's symptoms disappear with the maternal elimination of the food item, the doctor may suggest continued avoidance. If the symptoms do not disappear, the physician may ask the mother to avoid other food items or try a non-allergenic infant formula.

The popular skin prick test (SPT). Perhaps the most commonly used method to assess for food allergies, the skin prick test, is typically done using prepared glycerinated extracts or fresh food samples (Bahna, 2003b; Gold et al., 2003). Skin prick testing is relatively safe and easy to perform, though it has poor predictive value; false positives occur, and while the test can indicate sensitization, it does not indicate the *degree* of sensitivity (Garcia-Careaga & Kerner, 2005; Rosello & Huete, 2015; Woods, Thien, Raven, Walters, & Abramson, 2002). Other variables that can influence the test's reliability include: the extract quality, the patient's manifestations of sensitivity (e.g., gastrointestinal, skin, respiratory, cardiovascular, etc.), the experience of the test administrator, and current or recent patient medications (Bahna, 2003b).

The reliable radioallergosorbent test (RAST). A radioallergosorbent test or RAST is a test that detects the presence of Immunoglobulin E or G in a patient's blood (Rosello & Huete, 2015; see also Bahna, 2003b; M. Smith, 2015). It is important to note that Immunoglobulin E indicates the activation of the immune system in allergy while Immunoglobulin G tests only confirm exposure to the item (Bahna, 2003b). False negative radioallergosorbent test results are uncommon, making the test a good indicator of allergy (Garcia-Careaga & Kerner, 2005). See *Appendix G: Extended Definitions* for more information on RAST tests. The gold standard oral food challenge (OFC). The oral food challenge has been deemed the gold standard in the diagnosis of food allergy, though it is not always performed due to risk, time, and resource availability (Burks et al., 2012; Fung, Kim, & Spergel, 2013; Järvinen et al., 2009). Food challenges are used more frequently to determine if an individual is losing an allergy or to confirm a doubtful diagnosis and should be conducted in a hospital setting where epinephrine and other emergency resuscitative measures are available (Bahna, 2003b; Bindslev-Jensen, 1998; Burks et al., 2012; Garcia-Careaga & Kerner, 2005; Gold et al., 2003). During the test, the individual receives a small dose of the food item and, as long as no reaction occurs, increasing doses at timed intervals thereafter (Bahna, 2003b). The allergist carefully observes the individual and provides medical interventions if required—the test is complete after a 4-hour observation period following the last dose of the food item (Garcia-Careaga & Kerner, 2005; Järvinen et al., 2009).

The Food Allergy Epidemic

A number of seemingly interconnected hypotheses have been offered to explain the increasingly complex, multidimensional allergy epidemic (Velasquez-Manoff, 2012). Researchers have suggested that "genetic background alone" cannot account for the rapid growth in the number of individuals with food allergies (Ring et al., 2001, p. 702). Below, I will provide a brief overview of the broad theories that attempt to explain the surge in allergy. Additionally, I will briefly address the media's contribution to the creation of the food allergy epidemic. Individually, each hypothesis has some merit; however, collectively the suggested hypotheses intersect to present a distinct, though perplexing, emergent view of food allergy.

Hygiene hypothesis. The most widely accepted explanation for the rapid increase in food allergies is Strachan's "hygiene hypothesis" (Strachan, 1989, 2000). First posited in
relation to the hay fever epidemic of the postindustrial revolution (Emanuel, 1988), the hygiene hypothesis suggests unhygienic contact or cross-infection with older siblings offers a *protective* advantage against allergies in later born children (Strachan, 1989, 2000). As family sizes decrease and cleanliness increases, there are fewer familial "opportunit[ies] for cross infection" to challenge immune systems (Strachan, 1989, p. 1259; see also Sabra et al., 2003; Strachan, 2000).

The "old friends" or helminth hypothesis. The "old friends hypothesis" proposed by Rook, Martinelli, and Brunet (2003) parallels Strachan's (1989, 2000) hypothesis in that it addresses hygiene and sanitation, but differs in that it assumes an evolutionary perspective (Rook et al., 2003; see also Elliott, Summers, & Weinstock, 2007; Strachan, 1989, 2000; Velasquez-Manoff, 2012). The hypothesis suggests that bacteria and parasitic worms have co-evolved with their human hosts and serve to protect the body from immune-mediated illnesses (Rook et al., 2003; see also Elliott et al., 2007; M. Smith, 2015; Velasquez-Manoff, 2012). The rapid urbanization and sanitary reforms following the Industrial Revolution separated humans from nature, eliminating bacteria and helminths in developed countries. The result was a loss of immune system support (bacteria and helminths) and an increase in immune-related diseases (Elliott et al., 2007; Emanuel, 1988; M. Smith, 2015; Velasquez-Manoff, 2012). Current research suggests that we are in a global "epidemiological transition" that will see modern disease shift from "acute infectious to chronic degenerative diseases" such as inflammatory bowel disease, multiple sclerosis, asthma, diabetes, and allergy (Jackson, 2006, p. 13; see also Elliott et al., 2007; Rosenberg 2009; Velasquez-Manoff, 2012).

Toxin hypothesis. Profet's (1991) toxin hypothesis offers a "functional" evolutionary explanation for allergy, refuting the common belief that allergy is an "immunological mistake"

(Profet, 1991, p. 24). Instead, Profet argues an allergic reaction is the body's last line of defense in protecting itself from harm when primary physiological reactions such as vomiting, diarrhea, sneezing, coughing, tearing, or scratching fail to prevent toxins from entering the bloodstream. The idea of the body's "instinctive avoidance" of peanut products was previously documented by Fries's (1982) review of the medical case histories of 30 of his patients (most aged a few months to 6 years) who presented as clinically reactive to peanuts (p. 225). The adverse responses to peanut products included: three children who were troubled by the odor alone, seven who refused to consume peanuts, and one child with a "distaste" who refused to swallow, suggesting an innate "protective mechanism" was at work (Fries, 1982, p. 225).

Birth order and concentration of immunoglobulin E in cord blood. The decades following the discovery of Immunoglobulin E (Ishizaka, Ishizaka, & Hornbrook, 1966) saw increased research into the screening and early identification of "high allergic risk" infants for the purposes of implementing allergy reduction strategies (Varonier, Lacourt, & Assimacopoulos, 1991, p. 844; see also Croner, Kjellman, Eriksson, & Roth, 1982). Though some researchers have questioned the predictive capacity of cord blood IgE tests (Bergmann, Edenharter et al., 1997; Varonier et al., 1991), other studies have found that high levels of Immunoglobulin E in cord blood seem to *predispose* children to atopy (Karmaus, Arshad, & Mattes, 2001; see also Croner et al., 1982; Magnusson, 1988). Of particular note, Karmaus et al.'s (2001) study of 1,218 children born on the Isle of Wight, England between January of 1989 and February of 1990 found high levels of Immunoglobulin E in firstborn children as compared to their later born siblings. The study findings suggest that with each pregnancy a woman experiences, her immune system changes, thereby decreasing levels of Immunoglobulin E exposure, which in turn reduces the likelihood of having a child with atopic tendencies (Karmaus et al., 2001). Kusunoki et al.'s (2012) more recent study of 11,454 Japanese children aged 7–15 found a significant birth order effect where firstborn children were more likely to develop allergic diseases such as eczema, allergic rhinitis, allergic conjunctivitis, and food allergies than their later born siblings. The research team of Kusunoki et al. suggested the hygiene hypothesis (see *Hygiene hypothesis* above) in conjunction with Karmaus et al.'s (2001) prenatal origin hypothesis may explain their birth order effect findings (Kusunoki et al., 2012; see also Karmaus et al., 2001).

Mother's age at delivery. The age at which a woman has her first child is on the rise in the Western world (Ring et al., 2001). Dioun, Harris, and Hibberd (2003) studied the relationship between maternal age at time of delivery and the incidence of food allergies in Massachusetts. The researchers noted that maternal age in Massachusetts was on the rise, and by 1996 more women over age 30 were giving birth compared to their younger counterparts (Dioun, et al., 2003). The study revealed a correlation between the incidence of food allergies and maternal age which suggested women over 30 were three times more likely to have a child who developed food allergies as compared to their younger counterparts (Dioun et al., 2003). Additionally, the research revealed an increased chance of food allergies for firstborn children in particular (Dioun et al., 2003). These researchers connected their findings to Strachan's (1989, 2000) hygiene hypothesis by positing that women who are from smaller families had already reduced opportunities for cross infection, and the delay in having their own children subsequently increased the risk of having a child with food allergies (Dioun et al., 2003).

Mode of delivery. Researchers have found that microbes play a protective role against disease and a functional role in immunity and digestion (Reid, 2004). Specifically, the intestinal microbes that pass from mother to child during a vaginal delivery are similar to the mother's

intestinal flora and have been found to be different from intestinal microbes that a caesareanborn baby acquires in the external environment (Reid, 2004; Renz-Polster et al., 2005). The increase in caesarean births in developed countries over the last 30 years has paralleled the increase in allergic disease (Belizán, Althabe, & Cafferata, 2007; Guihard & Blondel, 2001; Husslein, 2001; Liu et al., 2004; Matthews et al., 2003). In their retrospective study of 8,953 children in Portland, Oregon, aged 3 to 10 years with diagnosed allergic rhinitis, asthma, eczema, or food allergies, Renz-Polster et al. (2005) determined that the risk of developing any allergic disease was higher in children who were born by caesarean section than those delivered vaginally. The authors found significant correlations between caesarean births and the development of allergic rhinitis, and between caesarean births and asthma in baby girls (Renz-Polster et al., 2005). Further, they discussed the possible connection to the hygiene hypothesis and described how a vaginal delivery seems to better support the immune systems of children. Interestingly, it was the babies born to mothers who had elected caesarean births that had the highest chance of developing atopic conditions, likely due to the effects of the caesarian delivery combined with the use of postnatal antibiotics that would "suppress the intestinal flora" in the newborn (Renz-Polster et al., 2005, p. 1470).

Birth season and vitamin D. Keet et al.'s (2012) study of the relationship between birth month and food allergy found that fall-born babies were the most likely, with winter-born babies next likely, to develop food allergies as compared to spring- and summer-born children. The researchers explained that babies born in the fall potentially have less vitamin D exposure from ultraviolet light, and since vitamin D is important in immune system function, it may be partly responsible for a compromised skin barrier which could in turn set the allergic sequence in motion (Keet et al., 2012). They also found that fall birth was a risk factor only for Caucasian

individuals and those with a history of eczema, further suggesting that early skin exposure to the sun can protect against inflammation and later food allergies (Keet et al., 2012). Their study supports the earlier work of Vassallo et al. (2010), who similarly investigated the relationship between birth season and food allergy using a sample of 1,002 participants living in Boston, Massachusetts. Vassallo et al. (2010) noted an association between fall or winter births in children aged 5 or younger who had food allergies.

Injected medicines. Dr. Alexander Wood's use of the hypodermic needle in 1853 introduced medical personnel to injection under the skin as a way to administer medication (Howard-Jones, 1947; see also Herrmann, 1994). By the early decades of the 20th century, concerns about the spread of disease resulted in mass injections for the prevention of scarlet fever, tetanus, and diphtheria, which sometimes resulted in serum sickness (Vaughn, 1941). The incidence of serum sickness that sometimes ensued following an antitoxin injection lends support to the theory that anaphylaxis is a human-made malady (Vaughn, 1941). Beginning in the 1940s, peanut oil was added to penicillin injections to support a slow release of the drug into the body, which subsequently resulted in allergic and anaphylactic reactions in many individuals (Guthe, Idsöe, & Willcox, 1958).

The role of the media. By the 1980s, food allergy was a largely "discredited phenomenon," but the incidence of fatal or near-fatal anaphylaxis in the 1990s brought food allergy back into the "medical and media spotlight" (M. Smith, 2015, p. 14). The risk narrative, documented in Canadian media has also helped to increase awareness around the everyday dangers for those who live with food allergies (Harrington, Elliott, & Clarke, 2011). The doubling of peanut allergies in industrialized countries over the last 20 years (Gruchalla & Sampson, 2015; see also Muñoz-Furlong, 2006; Rosello & Huete, 2015) has made "anaphylactic

allergy a major public-health issue" (M. Smith, 2015, p. 14). Waggoner's (2013) exploration of the "peanut panic" as one aspect of the food allergy epidemic further suggests the social coconstruction of allergy as cause for medical, scientific, educational, commercial, and public concern (Waggoner, 2013, p. 51; see also Nettleton et al., 2009).

Prevalence of Food Allergy

Due to the changing nature of allergic disease and perhaps as a result of individual access to medical care, it is difficult to provide a current and accurate report of the incidence of food allergy (Burks et al., 2012). In a 2007 study on prevalence of food allergy, Cruz et al. (2007) found that allergists estimated the occurrence of food allergy to be 4.6% of the population, compared to 17.1% and 17.6% as reported by non-allergist and otolaryngologists respectively. Research suggests that food allergy is one of the most commonly self-diagnosed health issues (Altman & Chiaramonte, 1996; Bahna, 2003b).

Though an accurate report on the prevalence of food allergy among the Canadian population is hard to produce, current estimates suggest 2% or approximately 700,000 people are living with food allergies in Canada (Canadian Society of Allergy and Clinical Immunology, 2014, p. 6). These figures align with British and Dutch studies that suggest 1.4% of adults and 5–7% of children are affected by food allergies (Bindslev-Jensen, 1998). Similarly, Australian studies indicate between 12 and 25% of the population having been affected by food allergies while true prevalence indicates that closer to 1.3% of adults have allergies (Woods et al., 2002). North American estimates indicate that 4% of adults and 8% of children are allergic to a food item (M. Smith, 2015). Self-reports indicate that upwards of 18–25% of Americans believe they have experienced a food allergy, while the actual confirmed percentages seem to be around 2% in adults and 2–8% in children (Burks, et al., 2012; Garcia-Careaga & Kerner, 2005).

Common Food Allergens

The extant literature attributes allergic reactions to more than 170 food items (Burks et al., 2012). While an allergic or anaphylactic responses can be triggered by any food item at any time, research reports that upwards of 90% of all food allergy reactions are caused by these priority allergens: peanut, tree nut, eggs, milk, soy, wheat, fish, shellfish, sesame, sulphites, and mustard (Bindslev-Jensen, 1998; Burks et al., 2012; DeVoe, 2008; Garcia-Careaga & Kerner, 2005; Gold et al., 2003; Government of Canada, 2015; Rosello & Huete, 2015). The most common food allergens affecting children are: peanut, tree nut, milk, eggs, soy, fish, and wheat, although older pediatric patients commonly have issues with berries and chocolate as well (Garcia-Careaga & Kerner, 2005). With regard to *outgrowing* allergies, research suggests that 90% of milk allergies in infants are resolved by age 3 and that 50% of children allergic to eggs do eventually outgrow their allergies (Bindslev-Jensen, 1998). While it is believed that many allergies can self-resolve, some, namely allergies to peanuts, nuts, fish, and shellfish almost always persist into adulthood (Bindslev-Jensen, 1998; Burks et al., 2012; DeVoe, 2008; Fries, 1982; Garcia-Careaga & Kerner, 2005; Rosello & Huete, 2015; Rouf et al., 2011). Additionally, some people who have never had food allergies develop adult-onset allergies, most commonly to shellfish, followed closely by tree nuts and then fish, soy, and peanuts (Kamdar et al., 2015). The research around adult-onset allergies indicates that late-onset allergies typically occur in a person's 30s and are more likely to affect women than men (Kamdar et al., 2015). Rare food allergens reported in the literature to have caused anaphylaxis include food items such as: arugula and cauliflower-both members of the Cruciferae family which includes other foods such as broccoli, cabbage, and mustard (Garcia, Carnes, Cedena, & Nieto, 2014; Hernández,

Quirce, Villalba, Cuesta, & Sastre, 2005); as well as young garlic—a member of the Liliaceae family which includes foods like leek, onion, and asparagus (Pérez-Pimiento et al., 1999).

Food Allergies in Relation to Eczema, Allergic Rhinitis, and Asthma

Children and young adults have been affected by the increase in the incidence of atopic conditions at a higher rate than adults (Peroni, Chatzimichail, & Boner, 2002). Children with food allergies are 4 times as likely than their non-food-allergic counterparts to have asthma, 3.6 times as likely to have respiratory allergies, and 2.4 times as likely to have eczema (Burks et al., 2012; see also Crain, 2011). While food allergies are believed to be the cause of one third to one half of all cases of childhood eczema (Bahna, 2003a; Wüthrich, 1998), some researchers suggest that the broken skin (from atopic dermatitis) offers allergens a sensitization route, which could also explain the common coexistence of food allergies and eczema (Thompson & Hanifin, 2005). Children who have eczema often have food allergies and asthma (Burks et al., 2012; Crain, 2011). In their Spanish study of 74 individuals with atopic dermatitis, the majority (90%) of whom were under age 16, Oehling, Resano, Sanz, and Fernández Benítez (1998) reported that 62.2% of participants had coexisting asthma and 17.5% had coexisting allergic rhinitis (Oehling et al., 1998). The researchers identified milk, eggs, fish, and nuts as the allergens that are most likely to affect the skin. It should be noted that although eczema and asthma are frequently found in individuals with food allergies, the food allergen itself does not typically trigger the asthmatic response; however, having coexisting asthma does put the person who is having a food-allergic reaction at a higher risk for anaphylaxis (Kemp, 2003; see also Bock, Muñoz-Furlong, & Sampson, 2001; Burks et al., 2012; Macdougall, Cant, & Colver, 2002; Russell & Huber, 2013). Consequently, individuals with food allergies and asthma are believed to have an "increased risk for anaphylaxis" (Robinson & Ficca, 2012, p. 187; see also Bahna, 2003a; Crain,

2011; Sabra et al., 2003) upwards of 5 times greater than food allergies alone (Iribarren, Tolstykh, Miller, & Eisner, 2010).

Signs and Symptoms of Food-Allergic Reactions

Food allergies can be unpredictable and can vary from mild to life-threatening reactions involving a single organ or several organ systems including: the gastrointestinal tract, the skin, the respiratory system, and the cardiovascular system (Cruz et al., 2007; Kumar et al., 2005). Allergic manifestations specific to each of the four organ systems will be discussed in the subsections below as well as a few other rare but well-documented signs and symptoms associated with allergic response in other body systems.

Most likely to react. With respect to food allergy, the gastrointestinal tract serves both a nutritive and an immunologic function in that it must select necessary nutrients and avoid harmful food protein allergens (Sabra et al., 2003). The gastrointestinal tract is the organ most likely to be affected by food allergens, though symptoms are not always apparent (Bahna, 2003a). Noticeable symptoms can occur from mouth to anus and may include: oropharyngeal itching or burning, metallic taste, dysphagia, nausea, abdominal cramping, vomiting, and diarrhea (Burks et al., 2012; Cruz et al., 2007; Garcia-Careaga & Kerner, 2005; Hernández et al., 2005; Kumar et al., 2005; Robinson & Ficca, 2012). Common symptoms in infants include colic, gastroesophageal reflux, inflammation of the esophagus, abdominal pain, vomiting, and/or diarrhea (Bahna, 2003a; Garcia-Careaga & Kerner, 2005). The passage of bloody stools in infancy as a result of milk intolerance is well documented in food allergy literature as well (Berezin, Schwarz, Glassman, Davidian, & Newman, 1989). The introduction of the HemoQuant test 1983 by Schwartz, Dahl, Ellefson, and Ahlquist (1983) provided researchers with a way to quantify infant blood loss from the gastrointestinal tract (Schwartz et al., 1983; see

also Ahlquist et al., 1984; Berezin et al., 1989; Ziegler et al., 1990). In their study of gastrointestinal blood loss in infancy, Ziegler et al. (1990) found that infants who drink cow's milk have more blood in their stools and lower iron levels than their breast-fed counterparts. Similarly, Berezin et al.'s (1989) study of 22 infants diagnosed as having milk protein intolerance, found that the presence of bloody stool was the primary symptom of soy and cow's milk protein intolerance.

Signs and symptoms of the skin. In approximately 80% of allergic reactions caused by food, individuals will experience both skin and respiratory symptoms (Robinson & Ficca, 2012). Skin specific manifestations or changes due to allergy can include: warmth, redness, a rash of itchy hives affecting the upper layers of the skin, or swelling under the skin, especially near the eyes, mouth, hands, feet, or genitalia (American Academy of Allergy, Asthma and Immunology, 2015; Gold et al., 2003).

Respiratory symptoms. While the severity of the allergic reaction depends on the amount of exposure to the allergen, common respiratory symptoms resemble those of asthma and can include one or all of the following: cough, congestion, wheezing, bronchospasm, rhinitis, and a hypersecretion of mucous (American Academy of Allergy, Asthma and Immunology, 2015; Robinson & Ficca, 2012; Sabra et al., 2003; Vilke, 2002). It is important to note that although respiratory symptoms do not commonly indicate a food allergy on their own, they *do* occur frequently with children who have pre-existing eczema (Bahna, 2003a; Cruz et al., 2007).

Cardiovascular symptoms. Allergic reactions to food can result in cardiovascular symptoms such as: chest pain, tachycardia, arrhythmia, a weakened pulse, low blood pressure, pale or blue coloured appearance to the skin, dizziness, shock, altered levels of consciousness, fainting, or cardiac arrest (American Academy of Allergy, Asthma and Immunology, 2015;

Burks et al., 2012; Kumar et al., 2005; Lieberman & Simons, 2015; Robinson & Ficca, 2012; Vilke, 2002). In Worm et al.'s (2012) 4-year study of pediatric and adult patients from 83 Central European medical centres specializing in allergy, participants reported a total of 8,836 symptoms in 2012 anaphylactic reactions. Cardiovascular symptoms were registered in 72% of the patients who experienced anaphylactic reactions and were more likely to be associated with "life-threatening situations and anaphylactic fatalities" (Worm et al., 2012, p. 692; see also Lieberman & Simons, 2015).

Other symptoms. Sometimes symptoms of a food allergic reaction include behavioural responses such as anxiety, irritability, or a sense of impending doom (Burks et al., 2012). A change in voice, difficulty speaking, or drooling have also been reported (Lee & Greenes, 2000; Sheffer & Austen, 1980). Some people have been known to experience headaches, migraines, or seizures, and women have reported uterine contractions (American Academy of Allergy, Asthma and Immunology, 2015; Bahna, 2003a; Burks et al., 2012; Robinson & Ficca, 2012).

Anaphylaxis as a Life-Threatening Phenomenon

The most serious symptoms of a food-allergic reaction include a quick drop in blood pressure, skin eruptions such as hives or rash, and acute swelling of the airway that can result in death (M. Smith, 2015). Symptoms are considered "consistent with anaphylaxis if they occur rapidly within minutes to several hours after exposure and affect at least 2 major organ systems" (Järvinen et al., 2008, p. 134; see also American Academy of Allergy, Asthma and Immunology, 2015; Lieberman & Simons, 2015). It is important to note, however, that "low blood pressure alone . . . in the absence of other symptoms can also represent anaphylaxis" (Canadian Society of Allergy and Clinical Immunology, 2014, p. 3). In the subsections below, I will discuss food, medication, insect stings, latex allergens, and allergen immunotherapy as causative agents of an

anaphylactic response. As well, I will address relevant aspects of exercise-induced anaphylaxis and food-dependent exercise-induced anaphylaxis.

Food allergens as the most common cause of anaphylaxis. Although numerous foods have been known to cause anaphylaxis in individuals (H. Sampson, 2003; see also Gangur, Kelly, & Navuluri, 2005; Garcia et al., 2014; Hernández et al., 2005; Pérez-Pimiento et al., 1999), the most common triggers of *known* anaphylactic reactions are peanuts, tree nuts, fish, and shellfish (Sampson, 2003; see also Kumar et al., 2005; Macdougall et al., 2002; Moneret-Vautrin et al., 1994; Sabra et al., 2003). In addition to causing the most severe reactions, peanuts, tree nuts, fish, and shellfish are allergies that continue into adulthood whereas milk, eggs, and soy are believed to be outgrown (H. Sampson, 2003; see also Sicherer, 2013). Food allergy accounts for 81% of the anaphylactic reactions in children (Järvinen et al., 2008; 2009; see also H. Sampson, 2003), with peanuts, tree nuts, and milk being responsible for two thirds of reported anaphylactic reactions affecting children (Järvinen et al., 2008). Anaphylaxis risk factors affecting children with food allergies include: older age, pre-existing asthma, allergy to peanut or tree nuts, previous reactions to trace allergens, or previous reactions involving the respiratory system (Kemp, 2003; see also Järvinen et al., 2008).

Medications can trigger anaphylaxis. Following food, drugs are the second leading cause of anaphylactic reactions (Kumar et al., 2005). Antibiotic medications such as cephalosporin and penicillin (Kumar et al., 2005; Thong & Yeow-Chan, 2004; Toogood, 1987; Wade et al., 1989), nonsteroidal anti-inflammatory drugs (Lieberman & Simons, 2015), beta-blockers (Toogood, 1987; see also Kumar et al., 2005), muscle relaxants used during anesthesia and radio-contrast media (Thong & Yeow-Chan, 2004; see also Brockow & Ring, 2011).

The sting of anaphylaxis. Individuals can develop allergic reactions to the stings of

bees, wasps, hornets, and fire ants and occasionally to the bites or stings of ticks, spiders, and scorpions (Järvinen, 2009). Wasps and hornets can sting multiple times and are thus regarded as the most aggressive of the insects responsible for reactions (Järvinen, 2009). Typical allergic response to an insect sting or bite includes localized redness and swelling at the site that can progress to an anaphylactic reaction when organ systems away from the site react. Parents of children with severe food allergies may find they are more vigilant following a bite or sting due to their child's predisposition to food-induced anaphylaxis.

Latex-induced anaphylaxis. Natural rubber latex made from the sap of the *Hevea brasiliensis* tree is used in the manufacture of medical, household, and personal items such as: gloves, elastic bandages, dental equipment, balloons, toys, and sports equipment (Rosello & Huete, 2015). The first case of contact urticaria to latex was documented in 1979, and the first case of anaphylaxis, in 1988 (Nutter, 1979; Turjanmaa, Reunala, Tuimala, & Kärkkäinen, 1988). Currently, latex causes allergic reactions in 1% of people in industrialized countries (Rosello & Huete, 2015), mostly from dipped latex products such as gloves, balloons, and condoms (Pfizer, 2014b). Children, health care employees, and individuals with other atopic conditions have an increased risk of developing latex-induced anaphylaxis—people with food allergies might use latex cautiously (Birmingham & Suresh, 1999; Rosello & Huete, 2015; Suli et al., 2004).

Anaphylaxis brought on by vaccination. Anaphylactic reactions resulting from the administration of vaccinations, although rare, do occur (Cheng et al., 2015; Nokleby, 2006; Wood, 2013) and have been attributed to vaccine components such as: gelatin, egg or milk proteins, chicken protein, yeast, or preservatives such as thimerosal, aluminum, and phenoxyethanol (Wood, 2013; see also Georgitis & Fasano, 2001; Nokleby, 2006). Latex stoppers on bottles or plungers on syringes have also been documented as the cause of a

vaccination-related allergic reaction (Nokleby, 2006). The most commonly reported vaccine to cause an anaphylactic reaction is the measles, mumps, and rubella vaccine (Sakaguchi, Nakayama, & Inouye, 1996; see also Kelso, Jones, & Yunginger, 1993; Kelso, Mootrey, & Tsai, 1999). Current research supports the belief that the gelatin stabilizer in the vaccine is the cause of the reaction, not the egg protein as previously thought (Sakaguchi et al, 1996; see also Kelso et al., 1999). Yellow fever vaccine, which is made using infected chicken embryos and contains gelatin made from bovine or porcine tissue proteins, has also been known to cause allergic reactions (Kelso et al., 1999). For this reason, individuals who are allergic to eggs, chicken, or gelatin are typically not given the yellow fever vaccine (Kelso et al., 1999). Other vaccination-related anaphylactic reactions have occurred following immunizations given to prevent: rabies (Popa & Lerner, 1984), influenza (Nagao, Fujisawa, Ihara, & Kino, 2016), the H1N1 strand of influenza virus (Rouleau et al., 2013), diphtheria, tetanus, and pertussis (Georgitis & Fasano, 2001), as well as the human papillomavirus (Brotherton et al., 2008).

Allergen immunotherapy may cause anaphylaxis. First introduced in relation to hay fever in 1911 by physicians Leonard Noon and John Freeman (Vaughan, 1941; see also Cohen, 2003; Larsen et al., 2016), allergen immunotherapy involves the intentional exposure to an allergen for the purpose of altering the body's immunological response to the allergen (Larsen et al., 2016). Current forms of allergen immunotherapy include: subcutaneous immunotherapy (SCIT), sublingual immunotherapy (SLIT), and oral food allergen immunotherapy (OIT). Most relevant to my research study, oral food allergen immunotherapy continues to be experimental and should take place only in settings where there is immediate access to emergency care due to the potential risk of systemic anaphylactic reactions (Vadlamudi & Shaker, 2015; see also Anagnostou et al., 2015; Oppenheimer et al., 1992).

Exercise-induced anaphylaxis. A unique case of unspecified exercise-induced anaphylaxis presented by Kidd, Cohen, Sosman, and Fink (1983) noted anaphylaxis in a 29-yearold athletic male brought on by exercise within 2 hours of eating *any* food despite subsequent skin and radioallergosorbent tests being negative (Kidd et al., 1983; Volcheck & Li, 1997). Documented cases suggest that exercise-induced anaphylaxis occurs most often in individuals who are accomplished athletes, though symptoms do not necessarily depend on the level of intensity of the exercise and do not necessarily occur at each exercise session (Sheffer & Austen, 1980; Wade, et al., 1989). Respiratory symptoms typically manifest as swelling of the upper airway, choking, wheezing, stridor, or tightness of the chest (Sheffer & Austen, 1980). In more serious cases, symptoms progress to nausea, diarrhea, vomiting, and a drop in blood pressure that leads to collapse (Sheffer & Austen, 1980; see also Shadick et al., 1999; Volcheck & Li, 1997; Wade et al., 1989). Headaches that have accompanied exercise-induced anaphylaxis, have been reported to last for many days (Sheffer & Austen, 1980). Worth noting, jogging is the most common physical activity associated with exercise-induced anaphylaxis although other activities such as walking, biking, aerobics, dancing, skiing, shoveling snow, riding horses and using a stairmaster have also caused a reaction (Shadick et al., 1999; Wade et al., 1989). Both Shadick et al.'s (1999) and H. Smith, Hare, Hoggarth, & Assam's (1985) studies have each reported one case where women experienced exercise-induced anaphylaxis during childbirth.

Food-dependent exercise-induced anaphylaxis (FDEIA). Though the term was coined by Kidd et al. (1983), symptoms of food-dependent exercise-induced anaphylaxis (FDEIA) were first reported by Maulitz, Pratt, and Schocket (1979) in their description of a 31year-old male patient with a confirmed penicillin allergy who, on three occasions, experienced anaphylactic reactions while running, after having previously consumed shrimp or oysters (Kidd et al., 1983; Maulitz et al., 1979). Current research suggests that physical activity following exposure to a food allergen may in fact "increase the absorption of recently-ingested, but partially-digested food proteins" (Romano et al., 2012, p. 1644; see also Adachi et al., 2008). Other researchers have posited that exercise increases histamine release, especially in the presence of Immunoglobulin E, which contributes to the anaphylactic response that some people experience (Kidd et al., 1983; see also Baek, Bae, Cho, Moon, & Kim, 2010; Barg et al., 2008; Medveczky, 2014).

To date, food-dependent exercise-induced anaphylaxis is most commonly linked to celery, shellfish, and wheat (Baek et al., 2010; Barg et al., 2008; Binkley, 2002; Burks et al., 2012; Kidd et al., 1983; Maulitz et al., 1979; Medrala et al., 2014; Medveczky, 2014; Mobayed & Al-Nesf, 2014; Sato et al., 2009; Shadick et al., 1999; Sicherer 2013; Silverstein, Frommer, Dobozin & Rosen, 1986; Vilke, 2002; Wade et al., 1989). Other less frequent instances of fooddependent exercise-induced anaphylaxis have been associated with: peanut, eggs, milk, cheese, peach, corn, cabbage, tomatoes, strawberries, poppy seeds, and tofu (Adachi et al., 2008; Kütting & Brehler, 2000; Mobayed & Al-Nesf, 2014; Romano et al., 2012; Sato et al., 2009; Shadick et al., 1999; Wade et al., 1989).

Increased Risk of Anaphylaxis

Factors that may increase the risk of an anaphylactic response include, but are not limited to: age, cardiovascular disease, and chronic pulmonary disease (Lieberman & Simons, 2015). Medications used to treat cardiovascular disease also increase the risk of anaphylaxis and include both beta-adrenergic blockers which may prevent epinephrine from working (Lieberman & Simons, 2015; Stewart & Lockey, 1992); and angiotensin converting enzyme (ACE) inhibitors which can heighten an allergic response (Sweitzer, 2003). Nonsteroidal anti-inflammatory drugs (NSAIDs) have the potential to augment an anaphylactic reaction (Lieberman & Simons, 2015).

Emergency Treatment of Anaphylaxis

The first response in the emergency treatment of anaphylaxis, whether food, exercise, sting, or latex associated, should be the administration of epinephrine (Canadian Society of Allergy and Clinical Immunology, 2014; Järvinen et al., 2008). Depending on the manifestation of an individual's symptoms, additional treatments administered in a hospital setting may include, but are not limited to: antihistamines, intravenous fluids, oxygen, bronchodilators, and corticosteroids (Silverstein et al., 1986; see also Volcheck & Li, 1997).

About epinephrine. Upon recognition of the signs of anaphylaxis, prompt administration of epinephrine should occur. Current best practices suggest that the individual should lie down with lower limbs raised if possible, as previous fatalities have resulted from standing and moving (Burks et al., 2012). Injected into a person's mid–outer thigh during an anaphylactic reaction, epinephrine works to open restricted airways, improve blood pressure, and accelerate the heart rate (Anaphylaxis Canada, 2015; Canadian Society of Allergy and Clinical Immunology, 2014). A call for emergency help should be made as soon as possible.

At this time, two auto-injectable forms of epinephrine are available to Canadian patients by doctor prescription—EpiPen® and Allerject® (Canadian Society of Allergy and Clinical Immunology, 2014). Students with life-threatening food allergies are required to supply their own epinephrine injectors when at school, many carrying a dose on their person and providing the main office with another dose. Epinephrine should be stored in a location away from sunlight and away from extreme hot or cold temperatures (Järvinen, 2009). Manufactured by Pfizer Canada Inc., EpiPen® is used to treat anaphylaxis in adults or children who are over 30 kg while EpiPen® Jr. is administered to children who weigh between 15 and 30 kg (Pfizer Canada Inc., 2014a; see also Järvinen, 2009 for dosage). Sanofi Canada's Allerject® auto-injector is also available in the 0.15 mg dosage for children weighing between 15 and 30 kg and the 0.3 mg dose for adults or children weighing over 30 kg (Sanofi Canada, 2015; see also Järvinen, 2009 for dosage). Available in either French or English, Allerject® has a unique voice-assistance feature that provides guided instruction to any individual who is in the process of using the auto-injector (Sanofi Canada, 2015). If symptoms do not begin to resolve after the administration of epinephrine, a second dose can be administered as early as 5 minutes after the first (Canadian Society of Allergy and Clinical Immunology, 2014; Järvinen, 2009; Lieberman & Simons, 2015). Physicians may order diluted epinephrine to be administered intravenously for patients who are not responding to injected epinephrine (Järvinen, 2009).

The possibility of a biphasic reaction. Severity of biphasic reactions are reported to vary with responses ranging from less to more severe than the original event and have typically affected the same organ systems as in the initial reaction (Tole & Lieberman, 2007; see also Douglas et al., 1994; B. Stark & Sullivan, 1986). Ellis and Day's (2007) research suggests that biphasic reactions may be linked to the "undertreatment" of the original response (p. 69). Treatment for a biphasic reaction include the same therapies as the initial anaphylactic event might include (Tole & Lieberman, 2007), and thus it is recommended that people who are at risk for anaphylaxis have two doses of epinephrine with them at all times in case symptoms do not resolve with the first dose (Frew, 2011; Oren, Banerji, Clark, & Camargo, 2007). Since biphasic reactions have been documented in 1% to 23% of anaphylaxis cases (Stark & Sullivan, 1986; see also Ellis & Day, 2007; Oren et al., 2007; Tole & Lieberman, 2007) with most occurring within 8 hours of the initial event (Tole & Lieberman, 2007), it is important that individuals who receive epinephrine be transported by ambulance to a hospital. A biphasic response is believed

more likely to occur in individuals who are exposed to an offending allergen orally since the food or drug item continues to travel through the gastrointestinal tract (Tole & Lieberman, 2007). Researchers studying food-induced biphasic reactions in children identified "older age" and "challenges to peanuts as risk factors for anaphylaxis" (Järvinen et al., 2009, p. 1270), however tree nut and cow's milk also caused serious reactions (Järvinen et al., 2008).

Anaphylaxis Fatalities

Anaphylaxis is a rapid-onset medical emergency that has many different manifestations affecting multiple organ systems and, as such, can be difficult to diagnose and treat (Frew, 2011; Kumar et al., 2005; Lieberman & Simons, 2015). Although death due to food-induced anaphylaxis is rare, factors that have contributed to food-allergy fatalities include: denial of symptoms by parents, children, and teachers; reliance on oral antihistamines to treat symptoms; and misunderstanding the severity of a reaction (Canadian Society of Allergy and Clinical Immunology, 2014; Hay et al., 2006).

A review of 92 anaphylaxis deaths in Ontario, Canada from 1986–2011 found that 43% of the fatalities were caused by food, the most common allergen being peanut at 17% followed by tree nuts at 6.5%, seafood at 4.3%, and milk at 1% (Xu et al., 2014). Insect venom accounted for 33% of anaphylaxis-related deaths in Ontario, while medication was responsible for 17% of deaths (Xu et al., 2014). Of the food-induced deaths, 60% occurred outside of the home and 85% of affected individuals were aware of, or suspected, a food allergy (Xu et al., 2014). Teens with peanut allergies seem to have an increased risk of fatal anaphylaxis (Xu et al., 2014). Additional factors associated with anaphylaxis-related deaths over the 26-year period of the study included: delayed administration of epinephrine, coexisting asthma, the use of angiotensin-converting enzyme inhibitors, or the use of beta blockers (Xu et al., 2014). Findings

from the Ontario study are consistent with other studies that suggest that the majority of foodallergy fatalities have: occurred outside of the home; been associated with peanut, tree nut, fish or shellfish; and occurred in people who also have asthma (Bahna, 2003a; Burks et al., 2012; Kumar et al., 2005; Sheikh & Walker, 2002). A caution worth noting is that 12%–14% of anaphylaxis deaths could not be prevented despite early and repeated use of epinephrine (Burks et al., 2012; see also Bock et al., 2001; Kumar et al., 2005).

Prevention of Food Allergy

For individuals who have an identified food allergy, strict avoidance of foods containing offending allergens is the number one way to prevent a reaction (Burks et al., 2012; Garcia-Careaga & Kerner, 2005; Pitchforth et al., 2011; Rouf, et al., 2011). This does require both anticipation and planning around situations where food will be available and includes the recommendation to wear medical identification jewellry (Fries, 1982; Hay et al., 2006). It is also important that individuals and/or caregivers know what to look for when reviewing food labels. Many developed countries, Canada included, have implemented labelling laws which require *plain* language identification of common allergens or their derivatives on the packages of all food items (Government of Canada, 2015; see also Burks et al., 2012; Garcia-Careaga & Kerner, 2005). Canadian labelling laws will be addressed in a forthcoming section of this chapter.

Differing viewpoints exist with regards to the prevention of allergies in infants and children although a general allergy prevention lifestyle, which includes breastfeeding newborns exclusively for 4 to 6 months and living in a smoke-free home, is not disputed (Bergmann, Wahn et al., 1997b). Advice in the late 1990s and the early 2000s centred around tailoring preventative measures to stop the progression of the allergic march from eczema and food allergies to allergic rhinitis and asthma (Bergmann, Wahn et al., 1997b; Peroni et al., 2002). Allergen avoidance,

including maternal avoidance of peanuts and tree nuts during the lactation period (Garcia-Careaga & Kerner, 2005; see also Chandra, 2002; Zeiger, 2003) as well as the delayed introduction to food items were key messages provided to parents of young children at the time (Abrams & Becker, 2013; Sicherer, 2013). Current best practice thinking has shifted from *treatment* to *prevention* (Abrams & Becker, 2013), suggesting that tolerance to foods is "an active immune-mediated process that requires exposure to food" in early life (Burks et al., 2012, p. 915; see also Du Toit et al., 2013; Gruchalla & Sampson, 2015; Joneja, 2012; Sariachvili et al., 2009; Sicherer, 2013).

Is There a Cure for Food Allergies?

At this time there is no cure for food allergies (Anagnostou et al., 2015; Crain, 2011; Greenhawt, 2014; Oppenheimer et al., 1992; Sicherer, 2013). As previously discussed, currently, the approved treatments include avoidance of the offending allergen and administration of potentially life-saving emergency medications (McGowan & Wood, 2014; Moran, Vickery, & Burks, 2013). Researchers, however, continue to search for strategies that may effectively treat, cure, or ultimately eliminate food allergies, some of which include: early introduction to allergens (Anagnostou et al., 2015), oral food allergen immunotherapy (Vadlamudi & Shaker, 2015), food allergy herbal formula-2 (Wang & Li, 2012), and use of helminths (Elliott et al., 2007; Velasquez-Manoff, 2012).

Summary of Allergy and Anaphylaxis

In this first of three sections of the literature review, I considered the extant literature around allergy and anaphylaxis, including: the prevalence of food allergy, signs and symptoms of both allergic and anaphylactic reactions, as well as current treatment protocols. I felt it necessary to first immerse the reader in the breadth of allergy-related medical literature in order to establish an understanding of food allergy in a general sense prior to delving into daily life and school experiences with allergy and anaphylaxis.

A Day in the Life: Allergy, Anaphylaxis, and the Family

Food allergies are known to affect the quality of life of both allergic individuals and their family members (Bollinger et al., 2006; Crain, 2011; Fenton et al., 2011; Fenton, Elliott & Clarke, 2013; Greenhawt, 2014; Marklund, Wilde-Larsson, Ahlstedt, & Nordström, 2007; Pitchforth et al., 2011). Children and adolescents with life-threatening food-induced allergies note physical, social, and emotional barriers to full participation in *normal* daily life activities (Fenton et al., 2011, 2013; Marklund et al., 2007; Pitchforth et al., 2011). As the number of childhood diagnoses of food allergy are increasing, parents, most often mothers, are ultimately charged with the responsibility for keeping their children safe until a time when the transfer of responsibility from parent to child can occur (Rouf et al., 2011; see also Akeson, Worth, & Sheikh, 2007; Alanne, Laitinen, & Paavilainen, 2014; Fenton et al., 2011). Parents of children with food allergies report increased levels of stress due to a heightened sense of responsibility that pervades every aspect of physical, social, and emotional care (Bollinger et al., 2006; Rouf et al., 2011). In the subsections that follow, I explore a recurrent theme in the literature, that is, the ever-present desire to balance the physical safety with social and emotional normalcy (Graceffo, 2008).

Acquiring a Diagnosis

The changing nature and multiple manifestations of food allergy, combined with the absence of pathognomonic symptoms, make it difficult to diagnose and, at the same time, easy to misdiagnose (Cruz et al., 2007; see also Kumar et al., 2005; Larsen et al., 2016; Nettleton et al., 2009). Some parents have reported having difficulty navigating the medical system in order to acquire a food allergy diagnosis for their child, citing family physicians who did not take

symptoms seriously or understand the severity of the risks associated with the allergy (Pitchforth et al., 2011). Delayed referrals to specialists, coexisting medical conditions, and trouble narrowing the offending allergen(s) have also been reported as barriers to food allergy diagnosis (Pitchforth et al., 2011). For some parents (particularly those with children who have multiple food allergies), the presentation of their child's nonspecific symptoms combined with their own persistence and insistence on a diagnosis has resulted in the accusation of Munchausen's syndrome by proxy (Putnam, 2003) likely influenced by Meadow's (1985) research noting that "children who are alleged to be allergic to a great variety of food and drugs" is a "warning signal" of "factitious illness" (Meadow, 1985, p. 385). There does exist a small body of professional medical literature around the allergic form of Munchausen by proxy that identifies mothers (Schreier, 2002, 2004) and "young and inexperienced parents" as part of the problem, but also warns "inexperienced" physicians to avoid "colluding with parents in agreeing that an allergy may be involved" (Warner, 2005, p. 621; see also Meadow, 1985; Warner & Hathaway, 1984) which further complicates the process for parents seeking a diagnosis and treatment plan.

Allergen Avoidance

After a food allergy diagnosis is made, individuals are advised that to prevent an allergic reaction, strict avoidance of foods containing the offending allergens must be adhered to and that individuals should always carry epinephrine (Burks et al., 2012; Garcia-Careaga & Kerner, 2005; Pitchforth et al., 2011; Rouf, et al., 2011). A few select avoidance supports are outlined below.

Shopping and Canadian food labelling laws. As of August 4, 2012, new Canadian food labelling laws came into effect to help consumers who wish to make allergen-informed purchasing decisions. In brief, the changes include: (a) the addition of mustard seeds as a priority allergen to be identified when included as an ingredient; (b) the required identification of

gluten and sulphite ingredients on food labels of applicable products; (c) the use of common language to accompany scientific terms; and, (d) the naming of component ingredients as applicable to priority allergens (Government of Canada, 2015). The legislation around contains statements specifies that "if a 'Contains' statement is included on the label of a prepackaged product" it must "appear after the list of ingredients for the product, if any, without any intervening printed, written or graphic material" and must include information to communicate the applicable priority allergens, gluten, or sulphites (Government of Canada, 2015, p. 48) contained in the product. "Precautionary" labels such as "may contain," or "processed in a factory that also processes," continue to be "sources of frustration" and anxiety for individuals and caregivers of those with food allergies (Harada, 2012, p. 23; Warren et al., 2015) as the lack of allergen confirmation can lead to risky consumptive behaviours. An additional source of label frustration for individuals with food allergies extends beyond food items to include household items such as ant traps, bird feed, or craft items in addition to personal and baby care products such as soap, shampoo, lotions, sunscreen, or cosmetics which have been known to contain hidden or undeclared allergens (Food Allergy Canada, 2016; O'Neil, Zanovec, & Nicklas, 2011; Russell, Gosbee & Huber 2012; Russell & Huber, 2013; Weeks, 1996). The term hypoallergenic is also problematic for people avoiding trigger allergens as *hypo* refers to low allergen levels, not *without* allergens as many people believe (O'Neil et al., 2011).

Meal preparation. Following a child's food-allergic reaction and subsequent diagnosis, parents are "highly motivated to avoid recurrence" (Pitchforth et al., 2011, p. 257) and often build time-consuming processes into their daily life to avoid contact with offending allergens (Williams, Parra, & Elkin, 2009). In addition to reading food labels each time a product is purchased (Altschul, Scherrer, Muñoz-Furlong, & Sicherer, 2001; Herbert & Dahlquist, 2008),

many families put extra cautionary measures in place to protect the individual with food allergies from their offending allergen(s)—often involving the cleanliness of hands and food preparation surfaces (Pitchforth et al., 2011). Teens with food allergies have reported that the only place they really feel safe is at home (Marklund et al., 2007). Although many families choose *not* to have offending allergens in their home at all, some families do purchase food items that contain an individual's offending allergen so that other family members can eat the food. For these families, strategies such as separate cooking utensils and linens or specific cleaning protocols aim to reduce the likelihood of accidental cross-contamination and a subsequent reaction.

Eating away from home. For individuals with life-threatening food allergies, eating away from home at restaurants, school, or at a friend or relative's home can be very stressful Herbert & Dahlquist, 2008). Many people with food allergies find inquiring about ingredients, meal preparation techniques, and/or cross-contamination prevention strategies to be anxiety causing and/or frustrating. Teens in particular have reported feeling embarrassed being the centre of attention when communicating their needs and similarly perceive their dietary restrictions as a burden (Akeson et al., 2007; Marklund et al., 2007). Children and teens expressed feeling anxious, afraid, scared, or annoyed with others who they feel know about their allergy, yet seemingly disregard it (Fenton et al., 2011; Marklund et al., 2007). Anxiety around food consumption in restaurants is increased when food-service personnel cannot provide clear responses to questions or concerns about ingredients, or food-safety preparations (Marklund et al., 2007). Some restaurateurs view allergy risk management not only as a responsible business decision but also as an opportunity to capitalize on a growing consumer market (Kronenberg, 2012; see also Abbot, Byrd-Bredbenner, & Grasso, 2007).

Negotiating Social Situations

Akeson et al.'s (2007) study found that while that parents could "vividly recall" their child's early allergic reactions, many children could not recall a serious reaction—which is perhaps testament to the success of the allergy management and support strategies parents have put in place (p. 1215). Parents have discussed the need for "constant vigilance" amid the uncertainty of daily life with connections to control and trust echoed throughout the extant literature (Rouf et al., 2011, p. 51; see also Akeson, et al, 2007; Annunziato et al., 2012; Williams et al., 2009). Parents report that common experiences such as going to a restaurant, attending parties or sporting events, and travelling all come with inherent risks and often a social debate, which must be anticipated and addressed prior to and during the experience to minimize stress (Bollinger et al., 2006; G. Smith, 2012; M. Smith, 2015; Sodowick, 2012; Waggoner, 2013; Warren et al., 2015; Weiss, 2008; see also O'Neil et al., 2011).

Some parents, mostly mothers, wanting to prevent accidental exposures, restrict social activities, bring their own food to social events, or accompany their children for longer than other parents typically do (Bollinger et al., 2006; George & McQuaid, 2010; Herbert & Dahlquist, 2008; Rouf et al., 2011). There is a direct relationship between the number of food allergies a child has and the level of parent monitoring behaviours, which has resulted in positive outcomes, most notably in adolescence (Williams et al., 2009). In contrast, other studies suggest that strategies intended to protect may actually contribute to teens' report of social isolation as the most challenging aspect of life with food allergies, as many perceive a social stigma accompanies a food allergy diagnosis (Noone, Muñoz-Furlong & Sicherer, 2003; Pitchforth et al., 2011; see also Bollinger et al., 2006; Marklund et al., 2007; Rouf et al., 2011; M. Sampson et al., 2006). Perhaps most troubling is that the reported fear of social isolation has contributed to

teens choosing not to carry potentially life-saving epinephrine so as to not appear different from their non-allergic peers (Akeson et al., 2007).

In addition to supporting their children in avoiding trigger allergens and managing reactions, parents are responsible for supporting their children by communicating risks. Rouf et al. (2011) report that mothers have experienced social discomfort and dilemmas when trying to negotiate a balance between their child's health and upsetting family members or friends who unintentionally put their child at risk. Trust is a key aspect of shared care, and many parents have addressed altered relationships with family members (Rouf et al., 2011).

Emotional Well-Being

While the emotional well-being of children with life-threatening food allergies is of the utmost concern to their parents, it is the parent groups that have most often been studied (Annunziato et al., 2012; Bartnikas & Phipatanakul, 2015; Gunnarsson & Hydén, 2009; Gupta et al., 2010; Herbert, Dahlquist & Bollinger, 2012; LeBovidge et al., 2006, 2008; MacKenzie, Grundy, Glasbey, Dean, & Venter, 2015; Rouf et al., 2011; Springston et al., 2010; Warren et al., 2015; Williams et al., 2009). Here, I highlight aspects of well-being for children and parents.

Children and teens. Teens/young adults who have experienced anaphylaxis reportedly worry more about and assess their allergies as more severe than those who have not experienced anaphylaxis; similarly, they report having less autonomy and more protective parents (Herbert & Dahlquist, 2008). Interestingly, teens with severe food allergies did not *self-report* higher levels of anxiety or depression than their allergy-free peers and in fact reported fewer self-confidence concerns (Herbert & Dahlquist, 2008; see also Lyons & Forde, 2004). Conversely, *measures of anxiety* for teens/young adults with food allergies were higher than their non-allergic peers,

which could be due in part to the constant normal vigilance required to remain safe—more knowledge equating to more anxiety (Lyons & Forde, 2004; see also Annunziato et al., 2012).

Parents. Much of the psychosocial quality of life research around food allergy has focused on the parents of young children with food allergies (Williams et al., 2009) and almost exclusively on mothers, which may be due in large part to the traditional roles of women as primary caregivers (Warren et al., 2015; see also Bartnikas & Phipatanakul, 2015; Rouf et al., 2011). Using food allergy quality of life measures, Warren et al. (2015) found that mothers were significantly more empowered than fathers to care for their children with food allergies but had lower scores on food allergy quality of life than fathers. Like teens, parental burden seems to be the highest for parents who have the most knowledge about food allergy (Warren et al., 2015; see also Annunziato et al., 2012; Lyons & Forde, 2004).

Rouf et al. (2011) found that mothers of children recently diagnosed as having food allergies had similar experiences around: the emotional adjustment to allergy, the acknowledgement of risk and responsibility, and the negotiation of a social identity on behalf of their child. Regarding the emotional adjustment to food allergy, researchers noted mothers experienced, at various times, "trauma, grief, anxiety, and hope" (Rouf et al., 2011, p. 54). Parental worry increases significantly when children with food allergies begin school and the transfer of care from parents to other adults occurs (Bollinger et al., 2006) but decreases when there is greater length of time between allergic reactions (Rouf et al., 2011). Death has been identified as the greatest fear of parents who have children with food allergies (Noone et al., 2003). Compounding parental anxiety are media stories of children, teens, and young adults who, while engaged in *normal* behaviours like eating at school, kissing, or having a smoothie during the first week of university classes, died (Akeson et al., 2007; see also CTV News Montreal, 2016; Fries, 1982; G. Smith, 2005/2010; Vuchnich, 2015). Annunziato et al.'s (2012) assessment and use of mental health supports revealed that while most caregivers perceive a need for mental health supports to address food allergies, few receive help because of barriers such as awareness, availability, access, cost, and the feeling of being overwhelmed.

Transfer of Responsibility from Parent to Child

Although parents begin providing autonomy supports for their children at a young age (Williams et al., 2009), adolescence is noted as a particularly worrisome time for parents of children with food allergies as the transfer of responsibility often coincides with an increase in: time teens spend away from home, freedom to explore new life experiences, and opportunities for independent decision-making (Akeson et al., 2007; Rouf at al., 2011). Other concerns like securing safe summer/career employment and moving away for postsecondary studies begin to emerge in adolescence (Akeson et al., 2007). The successful transfer of responsibility for allergy management from parent to child involves more independent responsibility for risk-taking, decision-making, and self-advocacy (Fenton et al., 2011, 2013). Although some of the literature around responsibility discusses the potential for increased risk-taking behaviours of *other* teens whose lack of allergy knowledge can intentionally or unintentionally put their allergic peers at risk.

Summary of A Day in the Life: Allergy, Anaphylaxis, and the Family

In this second of three sections of the literature review, I shared an overview of the food allergy and anaphylaxis daily life literature, including: diagnosis acquisition, allergen avoidance, social negotiations, emotional well-being, and the transfer of food allergy responsibilities. Awareness of how food allergy can affect aspects of individual and familial life may enhance the understanding of the school experiences that will be addressed in the third section below.

Allergy and Anaphylaxis Go to School

Once viewed as a private medical issue (Vaughn, 1941), food allergy and anaphylaxis became a very *public* concern (Nettleton et al., 2009) in Canada following the tragic September 30, 2003 death of 13-year-old Sabrina Shannon who consumed French fries from her high school cafeteria that were believed to have been cross-contaminated with her offending allergen–cheese (G. Smith, 2005/2010). In this third section of the literature review, I use the *best interests of the student* model (Stefkovich, 2006) to frame the ethical considerations school leaders attend to when making decisions in the best interests of individuals with life-threatening food allergies and anaphylaxis.

Best Interests of the Student

The best interests of the student leadership and decision-making model situates the *individual* student at the core of ethical decision-making and applies the ethics of justice, critique, care, and the profession to resolve "complex dilemmas" (Shapiro & Stefkovich, 2005, p. x; see also Stefkovich, 2006; Stefkovich & Begley, 2007). Stefkovich (2006) addresses the intentionality of the student in the singular and suggests when an individual is "treated with fairness, justice, and caring," then an expectation of equity and a model to guide action results (p. 17; Stefkovich & Begley, 2007). It seems plausible that the implementation of the best interests model in practice has illuminated challenges around conflicting individual interests (Frick, 2011; Stefkovich, 2006) as well as individual versus group interests (Frick, 2011) as school leaders attempt to address the needs of *all* students in their care in order to "bring about the greatest amount of good" (Tuana, 2007, p. 371).

Ethic of Justice: Sabrina's Law (Bill 3)

An Act to protect anaphylactic students, more commonly known as *Sabrina's Law (Bill* 3), a first of its kind in Canada, came into effect January 1, 2006 in Ontario to help students

affected by allergies and anaphylaxis stay safe at school. Dave Levac, the Liberal MPP (and former high school principal) who introduced the Bill in June of 2002 felt the Bill would clarify procedures in schools in the name of "protection of a child" (Levac, as quoted in G. Smith, 2005/2010). Sabrina's Law requires each publicly funded school board in Ontario to create and maintain an anaphylaxis policy that must include detailed individualized plans for affected students, allergen reduction strategies, communication plans, and regular anaphylaxis training for employees (Bill 3, 2005). Further, individual student plans maintained by the school principal are to include pertinent information for school board employees (who are in contact with individual students) about individual student allergy triggers, emergency procedures, and the storage of epinephrine (*Bill 3*, 2005). With the number and type of allergies on the rise (George & McQuaid, 2010; H. Sampson, 2003), compounded by research suggesting that fatal foodinduced anaphylaxis more commonly affects "adolescents and young adults" at "restaurants or school" (George & McQuaid, 2010, p. 5; see also Hay et al., 2006; McIntyre et al., 2005; Sheetz et al., 2004), the "immunity" clause in Sabrina's Law protects employees who administer epinephrine to a student whom they believe is "experiencing an anaphylactic reaction" (Bill 3, 2005, p. 2). Since the most critical factor associated with death due to food-induced anaphylaxis has been the "failure to administer epinephrine promptly" (Hay et al., 2006, p. 479; see also McIntyre et al., 2005; Muñoz-Furlong, 2006; H. Sampson, 2003), the clause virtually eliminates the possibility that a life-saving injection would be withheld by school personnel until parental permission was granted.

Ethic of the Profession: A Review of Select Documents

In the subsections that follow, I review aspects of Ontario Ministry of Education and Ontario College of Teachers documents that are relevant to my study topic. The Ontario Ministry of Education's *Accepting Schools Act (Bill 13); 2012* and *Shaping a Culture of Respect in Our Schools.* Feeling safe and included in one's school community is a "necessary condition for student success" (*Bill 13,* 2012, p. 1). For students with life-threatening food allergies, a safe, accepting, and inclusive environment requires the understanding and commitment of the whole school community (*Bill 13,* 2012, p. 1). *Bill 13,* also known as the *Accepting Schools Act* (2012) is relevant to my research in that it addresses prevention and intervention strategies specific to bullying—a common school experience for students with food allergies (Shemesh et al., 2013). *Shaping a Culture of Respect in Our Schools* (2008) reinforces the belief that a safe school, built on a foundation of positive relationships, is a "prerequisite for learning" (*Shaping a Culture of Respect in Our Schools*, 2008, p. 1).

The Ontario College of Teachers' *Ethical Standards for the Teaching Profession*. Four ethical standards have been identified by the Ontario College of Teachers (OCT) as representative of a "vision of professional practice" for Ontario educators (Ontario College of Teachers, 2015a, p. 1). The ethics of "care," "respect," "trust," and "integrity" are meant not only to "inspire members" and "promote public trust" but to "guide ethical decisions and actions" as well (OCT, 2015a, p. 1). The ethical standard of care requires educators to be compassionate, accepting, and committed to the well-being of students which, in the case of my research, is essential to maintain the physical health and safety of students with life-threatening allergies. The ethical standard of respect asks teachers to "honour human dignity, emotional wellness and cognitive development" through the modeling of respect for "values" and "social justice" among other things (OCT, 2015a, p. 1). Relationship building is a standard of trust which, for the purpose of my research, serves alongside care as a guiding safety principle for students with food allergies and anaphylaxis. Reflection and moral action form the core of the ethical standard of integrity which, when upheld, serves as a model in the learning community.

The Ontario College of Teachers' Standards of Practice for the Teaching Profession. Developed as a "framework of principles . . . inherent in Ontario's teaching profession" the Ontario College of Teachers' Standards of Practice for the Teaching Profession aims to "convey a collective vision" of what it means to be an Ontario teacher (Ontario College of Teachers, 2015b, p. 1). The following five standards are intended to guide members' professionalism: "commitment to students and student learning," "leadership in learning communities," "ongoing professional learning," "professional knowledge" and "professional practice" (OCT, 2015b, p. 1). Educators who are committed to students "treat students equitably and with respect and are sensitive to factors that influence individual student learning" (OCT, 2015b, p. 1) which could include an awareness of individual students' food allergies. Teacher leaders who are required to "maintain and uphold...ethical standards" in schools can work as part of the school team to ensure that students with food allergies and anaphylaxis are treated with care, respect, and integrity (OCT, 2015b, p. 1). The professional learning, knowledge, and practice standards are linked in that they require teachers to commit to "ongoing professional learning," its application, and reflection on "ethics," and "research," in addition to "policies and legislation" (OCT, 2015b, p. 1). For educators who have students with food allergies and anaphylaxis in their classes, this could mean doing things such as: reviewing Sabrina's Law legislation, communicating with the affected student and her/his parents about a safety plan, addressing incidents of allergy teasing, or engaging in a conversation with a student who has food allergies about how best to include her/him in classroom lessons, activities, or celebrations.

The Ontario College of Teachers' Safety in Learning Environments: A Shared **Responsibility.** In April 2013, the Council of the Ontario College of Teachers released a professional advisory entitled Safety in Learning Environments: A Shared Responsibility (2013) which set out to "remind members that they are responsible for ensuring safe learning environments for their students" (Ontario College of Teachers, 2013, p. 2). The document provided two examples, one around bullying and the other about food allergies, to illustrate for educators the importance of "recognizing student vulnerability and acting to mitigate it" (p. 3). In the Safety in Learning Environments: A Shared Responsibility document, the Council also defined "places of learning" to include "classrooms, school buses, science and technological studies labs, schoolyards, cafeterias, gyms, off-site facilities and worksites, co-op educational programs and work placements, field trip locations, arenas and sporting venues" (p. 3). This definition is significant as it extends educator responsibility beyond the immediate walls of the classroom. The Council has suggested ways to "minimize the risks" and advises members to "know the special medical needs identified for students (such as allergies) as well as any accommodations or modifications that may be required" (Ontario College of Teachers, 2013, p. 5). Further, the advisory provides general advice to educators who are planning a learning activity. Though this section of the document does not address allergies specifically, an educator who is aware of a student with a food allergy could consider the 10 planning points provided (p. 5). Finally, in the section on "due diligence" educators are reminded that their professional responsibilities include "be[ing] aware and responsive to new and emerging safety concerns that affect students (such as food allergies)" (Ontario College of Teachers, 2013, p. 6) which serves to reiterate the need to be mindful of individual student allergies, while preparing for learning.

Ethic of Critique: Student Voice

Students living with food-induced allergies and anaphylaxis quickly learn that selfadvocacy can be a matter of life or death. Often, best interests decision-making processes exclude student (Frick, 2011; Mitra 2008, 2012; Shapiro & Stefkovich, 2005; Stefkovich, 2006; see also Fenton et al., 2013 regarding voice and impacted group allergy research) and parent voices, as may be the case in many school districts. An underlying ethic of critique suggests that those voices which have typically been silenced (Freire, 1970/2005; Shapiro & Stefkovich, 2005; Starratt, 1994; Stefkovich, 2006) should have opportunity to engage in the best interests decision-making processes that directly affect their physical, social, emotional, and cognitive well-being. Starratt (1994) proposed that the ethic of critique provides a "framework" for educators to move from "naiveté" to "awareness," allowing them to "confront the moral issues" (p. 47) in schools. Current studies suggest there is a lack of quality of life research in the extant literature from the perspective of adolescents living with food allergies (Marklund et al., 2007). Epp (1996) might argue that *not* inviting students with food allergies to contribute to the allergy dialogue would constitute an act of "systemic violence" as the "institutionalized practice adversely impacts" the student (p. 3). Since each individual with food allergies and anaphylaxis "reacts differently" (DeVoe, 2008, p. 29), each individual student's *lived experience* (Van Manen, 1990) and voice (Mitra, 2012) is central to ethical leadership and decision-making in schools.

Ethic of Care

The care ethic is one of "relation" (Noddings, 2012a, p. 771; see also Gilligan, 2003; Noddings 2006, 2012b, 2013; Starratt, 1994) in which the "dignity" of each person is honoured (Starratt, 1994, p. 52) by those in the relationship. Though Noddings (2012a) argues "many important relations . . . are not equal relations," she contends "both parties contribute to the establishment and maintenance of caring" (p. 772). When authentic caring relationships exist in school communities, there is a "sense of trust and safety" (Crippen, 2012, p. 196) that can serve to support students managing their allergies in the public realm. If the learning environment is one where student voice is honoured, students with allergies may feel better able to communicate their needs. In turn, educators have a responsibility to care for their students' cognitive *and* "affective" (Epp, 1996, p. 9) domains, either genuinely or ethically (Noddings, 2013). When school staff model caring behaviours, they not only attend to the individual's sense of belonging, but also establish an expectation of care (Stefkovich, 2006; Stefkovich & Begley, 2007), further reinforcing "communication" as "a key component of ethical behavior" (Tuana, 2007, p. 372).

Safety as care. For students with severe allergies to be able to engage in learning, they must first *be* and *feel* physiologically and contextually safe while in transit to/from school, on school property, and while participating in school-sanctioned activities, as this will provide an "optimal foundation for learning" (Devine & Cohen, 2007, p. 19; see also DeVoe, 2008). Being and feeling safe means that the student's physical body and learning spaces (also breathing spaces for aeroallergens) must be free from offending allergens. Activities or unfamiliar learning environments where consideration has not been given to a student's allergy needs can present challenges, as affected students have to quickly assess potential risks. Two aspects of care, emergency preparedness and prevention (Behrmann, 2010), will illuminate key issues below.

Emergency preparedness as care. Given the growth in the number of people living with allergies and anaphylaxis (George & McQuaid, 2010; H. Sampson, 2003), it is *likely* that educators will encounter a student who has the "potential" (Hay et al., 2006, p. 479) to have a severe allergic reaction at school. Of students with food allergies, 84% will experience an
allergic reaction at school (Powers et al., 2007; see also Berhmann, 2010); 24% will experience their first reaction at school (McIntyre et al., 2005; Muñoz-Furlong, 2006; see also Pistiner & Lee, 2012); and 79% of all reactions occurring at school will happen in the classroom (Sicherer, Furlong, DeSimone, & Sampson, 2001; see also Weiss, Muñoz-Furlong, Furlong, & Arbit, 2004). With varying degrees of emergency training provided, school personnel often report feeling unprepared to respond (Ercan, Ozen, Karatepe, Berber, & Cengizlier, 2012; Powers et al., 2007), noting that "medical needs go beyond . . . usual roles" (DeVoe, 2008, p. 30; see also Ravarotto et al., 2014). It is important that all staff members, including teachers (also substitutes), administrators, educational assistants, office personnel, and lunchroom supervisors not only know how to recognize the signs and symptoms of anaphylaxis, but also know where to locate and how to administer epinephrine (Muñoz-Furlong, 2006; see also Lewington, 2014). Russell and Huber (2013) strongly suggest that regular allergy training occur every 4 to 6 months instead of only at the very busy school start-up times (Russell & Huber, 2013).

The high cost of epinephrine as prohibitive to safe care. By August of 2016 in the United States, the cost for a two-pack of EpiPen® brand epinephrine auto-injectors skyrocketed in price to over \$600 which represents a 400% increase since 2009 (Hudes, 2016). Without a generic version of the drug or access to another manufacturer, some individuals who rely on the potentially life-saving device are concerned they can no longer afford the medication. Some Americans have begun to purchase epinephrine from suppliers in Canada, where the cost of an auto-injector is just over \$100 (Hudes, 2016; Woodyard & Layton, 2016). In Britain, where the price of a two-pack of injectors is approximately £53 or \$69 U.S. dollars, the government is involved in cost negotiations with suppliers, which is not the situation in the United States (Paton & Kresge, 2016). Amid pressure to reduce costs, Mylan, the American pharmaceutical

distributor of EpiPen® at the centre of the controversy indicated they would increase the number of patients who could apply to the company for financial assistance (Hudes, 2016).

Prevention: Food restrictions. The management of food allergy and anaphylaxis in schools is unique in that it often requires students, staff, and parental understanding, support, and compliance with the protective measures put in place to keep students with life-threatening food allergies safe (Pistiner & Lee, 2012). The food allergy discourse in school communities has the potential to become divisive due to conflicting value systems, especially in districts where food bans have been introduced—the most common ban being to peanuts (Russell & Huber, 2013). Due in part to the significant increase in the number of children with nut allergies, the severity of the allergic response, and the fact that many first-time reactions do happen at school (Pistiner & Lee, 2012), the peanut butter ban has proven to be an effective way to substantially reduce accidental exposures to the allergen (Banerjee et al., 2007). Those who oppose food restrictions, particularly to nuts, argue schools are "over-reacti[ng] to the magnitude of the threat," there is no "scientific evidence" that restrictions are "effective," and restrictions are actually "making things worse" (Christakis, 2008, p. 1384). Others have argued for students with food allergies to be homeschooled so as to not disrupt the lives of non-allergic students (Liston, 2011).

Common daily routines, like finding a safe place to eat lunch, can be problematic for a student living with life-threatening food-induced allergies and anaphylaxis. Instead of all-out bans, some schools have implemented segregated seating areas in lunch rooms for students with food allergies (Waggoner, 2013) so as to not trouble the families of non-allergic children (DeVoe, 2008). Designated safe areas, however, require vigilant monitoring of the space as well as attention to student interactions (Behrmann, 2010). In a recent Ontario study where children with food allergies shared their perceptions of risk, students reported that they felt high schools

were "less protected environments" than elementary schools due to personnel, routine,

supervision, and communication barriers (Fenton et al., 2011, p. 177). Additionally, there seems to exist a belief that high school students with severe food allergies require less systemic support to manage anaphylaxis in schools than their elementary counterparts, which is troubling given adolescents are at greater risk of death from anaphylaxis (Fenton et al., 2011; see also George & McQuaid, 2010; Hay et al., 2006; Lewington, 2014; Marklund et al., 2007; McIntyre et al., 2005; Russell & Huber, 2013; Sheetz et al., 2004; G. Smith, 2005/2010).

Bullying and isolation: Caring relationships. Although students with food-induced allergies want others to know about their allergies, it is this same public disclosure that makes them vulnerable to allergy-related teasing, bullying, or isolation and subsequently increases the likelihood that treatment will be delayed due to lack of communication (Marklund et al., 2007; Pitchforth et al., 2011; Russell & Huber, 2013; M. Sampson et al., 2006; see also Behrmann, 2010). As briefly touched on in Chapter One, upwards of 42% of children with food allergies and 50% of children with food allergies in grades 6 to 10 have reported being teased about their allergies and 30% have had their offending allergen waved at them in a threatening manner (Shemesh et al., 2013; see also Landau, 2010). Sadly, classmates were the perpetrators most of the time (Shemesh et al., 2013). Isolation of students with food allergies can occur in schools: (a) where designated and labelled safe spaces for students with food allergies exist (Landau, 2010); (b) when lesson materials including offending allergens are used (Berhmann, 2010; Hay et al, 2006; Russell & Huber, 2013); or (c) when lack of consideration on the part of the adults in the learning environment results in students feeling disregarded (Marklund et al., 2007). Students who have experienced social, emotional, or physical violence related to their allergies need to feel that if they go to the adults in their school(s) for support, their concerns will be

addressed (Frost, 2012; see also MacDonald, 1996); otherwise they will be less able to learn (Devine & Cohen, 2007; Shemesh et al., 2013). Fostering a culture of "empathy, kindness, and compassion" around food allergy is "incumbent on staff" (Russell & Huber, 2013).

Care as moral literacy instruction. School communities wishing to move knowledge about food allergies and anaphylaxis into purposeful action may use allergy as a basis for moral literacy instruction. The three components of moral literacy: ethics sensitivity, ethical reasoning, and moral imagination, "mutually reinforce one another" (Tuana, 2007, p. 366). Specifically, when educators come to more fully understand the needs of a student with food allergies and anaphylaxis, a relation of care is established which in turn strengthens communication processes, further inspiring moral literacy instruction. For example, ethics sensitivity includes the assessment of "moral intensity of a situation" and when applied to allergy, students and teachers could examine the "seriousness of the [potential] harm and/or the urgency of a response" (Tuana, 2007, p. 367). The development of ethical reasoning skills would focus on responsibility and consequence which could be used to deepen understanding about the reasons for certain anaphylaxis policies or procedures in schools. The third aspect of moral literacy instruction, moral imagination, as applied to allergy and anaphylaxis awareness, would require critical and creative thinking about possible ethical situations and prospective outcomes (Tuana, 2007). Case studies requiring empathetic and solution-focused problem solving around allergy and anaphylaxis are lacking in the extant literature but could serve to promote awareness and provide relevant instructional opportunities in school communities.

Summary of Allergy and Anaphylaxis Go To School

In this last of three sections of the literature review, I used the *best interests of the student model* (Stefkovich, 2006) as a framework for thinking about the ethical leadership and decision-

making practices school leaders might consider when acting in the best interests of individuals with food allergies and anaphylaxis. Specifically, I incorporated educational legislation, policies, processes, and practices into the four ethics of justice, the profession, critique, and care (Shapiro & Stefkovich, 2005; Stefkovich, 2006) to illuminate just how complex it can be to ensure the safe care of individuals with food allergies and anaphylaxis.

Summary of Chapter Two

In the review of the extant literature around the school experiences of students with lifethreatening food-induced allergy and anaphylaxis, I encountered numerous studies by medical professionals that provided insight into allergic disease and offered strategies for daily life management of the disease and its symptoms. Despite increasing interest and acceptance of qualitative health research (Morse, 2013), allergy and anaphylaxis research specifically, is "dominated by a broadly positivist paradigm" (Gallagher, Worth, & Sheikh, 2009, p. 1118). As a result, the majority of the health-related literature specific to allergy and anaphylaxis that I examined was quantitative in nature and based on objective testing of hypotheses.

The lack of qualitative health-related food allergy research became evident to me and its absence simultaneously loomed over and permeated almost all of the school-related food allergy literature I studied. Interestingly, many articles recommending policies, procedures, and strategies to ensure the safety of students with life-threatening food allergies in schools were written by medical professionals rather than educators, which in my view reinforces: (a) the primacy of the physical allergy experience over the social and/or emotional experiences; (b) the need for educators to share and access allergy information in educational mediums; (c) the need to build knowledge about allergy and anaphylaxis in school communities; and, (e) whose voice is currently valued as significant or relevant to the allergy and anaphylaxis discourse in schools.

With the exception of a few qualitative research studies (Akeson et al., 2007; Fenton et al., 2011, 2013; Marklund et al., 2007; Pitchforth et al., 2011), the voices of children/teens with life-threatening food allergies were essentially silent in the literature I reviewed—there were far more parent perspectives represented (Annunziato et al., 2012; Bartnikas & Phipatanakul, 2015; Gunnarsson & Hydén, 2009; Gupta et al., 2010; Herbert et al., 2012; LeBovidge et al., 2006; 2008; MacKenzie et al., 2015; Rouf et al., 2011; Springston et al., 2010; Warren et al., 2015; Williams et al., 2009). One might anticipate that as children living with food allergies age, and the number of individuals affected by allergic disease increases, the body of qualitative research around food allergy will grow. Similarly, the doubling of peanut allergies in industrialized countries over the last 20 years (Gruchalla & Sampson, 2015; Muñoz-Furlong, 2006; Rosello & Huete, 2015) will likely result in a "transition to adulthood" research opportunity that is currently not well developed in the literature—save the exception of a few media articles about safety and security in postsecondary institutions (Shackelford, 2013; Waggoner, 2013).

Regarding educational research around food allergy and anaphylaxis in schools, the literature is punctuated with issues-based discourse, primarily at the elementary school level. It seems there is a lesser focus on secondary student experiences despite research indicating teens with food allergies are at a greater risk of anaphylaxic death at school (Fenton et al., 2011, 2013; see also George & McQuaid, 2010; Hay et al., 2006; Lewington, 2014; Marklund et al., 2007; McIntyre et al., 2005; Sheetz et al., 2004; G. Smith, 2005/2010). Although I feel the school allergy and anaphylaxis dialogue is well positioned to address ethical leadership and the application of best interests decision-making (Shapiro & Stefkovich, 2005), only Behrmann's (2010) work directly addresses the ethics of food allergy policies in schools. I believe there is an opportunity to study the application of the elements of moral literacy instruction (Tuana, 2007)

to food allergy practices in schools. There exists a gap in academic school allergy research around families that homeschool their children who have life-threatening food allergies, instead of sending them to traditional schools (Bollinger et al., 2006). In their study of 87 families participating in a University of Maryland Allergy Practice research study into the impact of food allergies on daily life, Bollinger et al. (2006) discovered that 10% of participants homeschool their children (p. 417). A search of *homeschool* and *allergy* in EBSCOhost, Scholar's Portal, and ProQuest databases uncovered only two academic articles that made mention of food allergies as a reason to homeschool—and interestingly one article referenced the first (Gaither, 2009; see also Johnson, 2013). Conversely, an internet search produced 327,000 results which included personal blogs, websites, social media sites, and mainstream media articles.

In the hundreds of studies I examined for the literature review, not once did I encounter qualitative school-allergy research that considered the perspectives of students, parents, teachers, and administrators in the same study. Being both the parent of a teen with life-threatening foodinduced allergies and anaphylaxis, as well as an educator, I feel my research study provides an opportunity to illuminate participants' perspectives on their experiences, which may in turn serve to improve current policies, process, and practices in place in schools. It is with the extant literature in mind that I proceed to Chapter Three where I share my methodology and method.

CHAPTER THREE: METHODOLOGY AND METHOD

In this chapter, I outline the methodology and method considered in the design and execution of my study around the school experiences of children with life-threatening foodinduced allergies and anaphylaxis. I begin by situating myself in the study so the reader may understand how my own lived experience as a mother of a teen with food allergies and as an educator has socially situated my perspective (Van Manen, 1990; see also Denzin & Lincoln, 2005). I continue with a brief discussion of qualitative research, one-on-one interviews, and case study research. I use subheadings to help organize and show how my selected methodology and methods are located within the interpretivist paradigm and are appropriately informed by and connected to my study questions (Agee, 2009; Merriam, 2009). I then provide an overview of the steps I followed in seeking permission from the Nipissing University Research Ethics Board to conduct my research with human participants. Ethical considerations are detailed, followed by an explanation of how I addressed issues of ethics and bias in both the construction and enactment of my qualitative case study research. Next, I share my sampling technique, detail the sample selection criteria I used to select potential interview participants, and outline the process I used to invite individuals to participate in an in-depth one-on-one interview around my study topic. I provide, as a support to the reader, brief introductory profiles of my study participants, as a collective and as individuals. Careful consideration was given to the selection of the participant interview locations, and I explain the measures I took to ensure the safety of the interview participants and their family members who may have allergies. I explain my data collection methods, including: one-on-one interviews, five General Schedules of Interview Questions, audio-recording, and the use of a field journal as a support tool (Lincoln & Guba, 1985). Next, I note aspects of internal and external validity that strengthen my study. I detail the process I used to interpret and analyze my data before concluding with a summary of the chapter.

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I Situate Myself in the Study

I feel it is important for the reader that I situate myself in the research study first and foremost as a mother of two children (one with life-threatening food allergies); as an educator with a keen interest in how children (and families) with food-induced allergies and anaphylaxis negotiate daily life at home, at school, and in the community; and as a doctoral student committed to researching student, parent, teacher, and administrator perceptions of the school experiences of students with life-threatening allergies and anaphylaxis.

I feel my parenting and educational experiences have informed my research questions and study purpose. As a mother, I have experienced many of the challenges associated with raising a child with food allergies as addressed in the extant literature; some of which include but are not limited to: accepting the diagnosis (Rouf et al., 2011), educating myself and others (Hahn, 2011; Hay et al., 2006), medical decision-making (Herbert, 2011), balancing "safety and normalcy" (Graceffo, 2008, p. iv), negotiating social situations (George & McQuaid, 2010), monitoring self-esteem (Molzon, 2008), addressing bullying (Shemesh et al., 2013), reacting in an emergency (H. Sampson, 2003), and advocating for my child (Gunnarsson & Hydén, 2009; Pitchforth et al., 2011) within educational contexts. As the parent of a teen with food allergies, it has been necessary to reframe my thinking, always being on alert, "never really free" from concern for potential risks to my child (Wilson-Forrest, 2007, p. i).

As a secondary school teacher who is currently in the role of a grade 7 to 12 curriculum coordinator, I am in a unique position in that I have the opportunity to visit all of the secondary schools and some of the elementary schools in my school board. In the course of my daily work with teachers and administrators, I often have access to classrooms, work rooms or offices to which other school visitors are not privy. As such, I have seen a wide range of allergy and anaphylaxis-related information and materials in schools: informational posters on how to

recognize the signs and symptoms of anaphylaxis; instructional texts explaining how to use an epinephrine auto-injector; and individual emergency plans for students on the walls of classrooms or in educator workspaces. My personal interest in the daily management of children with food allergies often intersects with my professional life, as I am attuned to the management artifacts (e.g., food allergy action plans, physician/parent permission forms for medication administration, etc.) and ways in which schools communicate with students, staff, and parents to address food allergy and anaphylaxis issues (Butler, 2005; Robinson & Ficca, 2012; Sheetz et al., 2004). I acknowledge that my life experiences and my "beliefs about reality, knowledge and value" have shaped my worldview and have significantly influenced my research journey (Rothe, 1994, p. 5; Van Manen, 1990).

Qualitative Research

My research questions and study purpose situate my inquiry within the interpretivist paradigm (Glesne, 2011; Merriam, 2009). In this tradition, a relativist ontology and subjectivist epistemology assume multiple realities that are "socially constructed, complex, and ever changing" (Glesne, 2011, p. 8; see also Denzin & Lincoln, 2005; Guba, 1990; Patton, 2002; Stake, 1995). With respect to my research, individual participants have their own interpretations and their own perceptions of the school experiences of children and teens who have severe food allergies and anaphylaxis. Quantitative methodology, in my view, is not compatible with my research questions or study purpose, as the positivist paradigm assumes an objective reality that does not involve perception or values of individuals and further positions the researcher and study participants as independent (Denzin & Lincoln, 2005; Guba, 1990; Sale, Lohfeld, & Brazil, 2002). As such, I believe qualitative methodologies place me in a better position to understand, contextualize, and share participants' emic perspectives and meanings in order to create new knowledge around the school experiences of children and/or teens with food allergies and anaphylaxis (Glesne, 2011; Mason, 2002; Maxwell, 2002; Merriam, 2009). While the aim of qualitative research is to "gain insight" into the social phenomenon that quantitative methods "cannot access," I acknowledge that my research study has ultimately been filtered through my own interpretive researcher lens and is inherently value laden (Sale et al., 2002, p. 44; see also Denzin & Lincoln, 2005; Glesne, 2006; Guba, 1990; Patton, 2002). Thus the importance of the relationship between the researcher and participant is reflected in my purpose, structure, and method of interviewing that I used to conduct my research (Seidman, 2013).

Interviewing in Qualitative Research

The aim of the qualitative research interview is to gather data in the participants' own words in order to understand, reconstruct, and make meaning of their experiences (Seidman, 2013; see also Bogdan & Biklen, 2007; Kvale & Brinkmann, 2009; Merriam, 2009; Patton, 2002; Stake 1995). With respect to my study, I was interested in learning from participants their perceptions of the school experiences of children and/or teens with life-threatening food-induced allergies and anaphylaxis. In addition to accessing the participants' perspectives, qualitative interviews allowed me to consider my research topic from a sociolinguistic perspective, as participant speech and language are fundamentally associated with individual thought and behaviour (Vygotsky, 1934/2012; see also Patton, 2002; Rieber & Robinson, 2004; Steiner, 1978). As such, I was interested in listening to and learning from the language my participants used, specifically around the use of labels as identifiers and the emotions of allergy, as it is my view that vocabulary may reflect individual or systemic values (Monteath & Cooper, 1997). An equally important aspect of the interview is the construction of knowledge that resulted from the social interaction and relationship between participant and researcher (Kvale & Brinkmann, 2009). Patton (2002) furthers this premise, positing that the quality of the information gleaned in an interview is dependent on the researcher. As I am both the mother of a teen with foodinduced allergies and anaphylaxis as well as an educator, I feel that I have access to *insider* knowledge and experiences that allowed me to pursue conversation threads that a researcher without similar parental or educational experiences would not necessarily have knowledge (Dwyer & Buckle, 2009). As I sought to learn participants' perceptions about the school experiences of students with food allergies and anaphylaxis, I felt qualitative interviews were appropriate to my research topic and study questions in that I was able to access experiential and perceptual data as well as participant meaning through language (Rieber & Robinson, 2004).

Case Study Research

A qualitative case study is used when the researcher is interested in exploring and describing a phenomenon in order to share a detailed account of it (Baxter & Jack, 2008; Merriam, 1998; Stake, 1995). As previously discussed in the Study Overview section of Chapter One, I was interested in learning "how" the "social experience" of being a child or teen with lifethreatening food-induced allergies and anaphylaxis "is created and given meaning" in schools (Denzin & Lincoln, 2005, p. 10). For the purposes of my research, the case study approach is *intrinsic* as I wanted to learn about the school experiences of students with severe food allergies and anaphylaxis rather than generalize about the topic (Stake, 1995, 2005; S. Stark & Torrance, 2005). It is my view that my case is *singular* as it is a "specific, unique, [and] bounded system" (Stake, 2005, p. 445) focusing on the school experiences of children/teens with severe food allergies. In order to reveal many different aspects of the phenomenon, I used multiple participants from four groups or data sources including: children/teens with food allergies, parents, teachers, and administrators (Baxter & Jack, 2008; Stake, 2005; S. Stark & Torrance, 2005). Using multiple participants supported data triangulation, interpretation, and analysis processes by illuminating my case and clarifying meanings (Baxter & Jack, 2008; Stake, 2005).

Important in case study research is the ability of the researcher to acknowledge that the "social, cultural, situational, and contextual" realities of the participants allow for personalized meanings to be constructed (Stake, 2005, p. 452). The research participants in my study had different and varied perspectives around the school experiences of children with food allergies and anaphylaxis. It was these participant perceptions that I wanted to access and draw out during the individual interviews. Equally important in my view is the *relationship* between researcher and individual participants as the relationship is central to meaning-making processes (Patton, 2002). As such, I believe my work is both descriptive and particularistic in nature, but also heuristic as well, as new meanings around the school experiences of students with severe food-induced allergies and anaphylaxis have emerged (Merriam, 1998).

Research Ethics Board: Permission to Conduct the Study

After completing the *Tri-Council Policy Statement 2: Course on Research Ethics* online tutorial and with my committee's approval of my proposed research, I submitted my completed ethical review protocol to the Nipissing University Research Ethics Board (as required by the university in the case of research with human participants) to seek permission from the Board to conduct my qualitative research as detailed in my completed protocol. I value institutional review as necessary to protect the potential participants from harm, to ensure informed consent, and to ensure ethical guidelines are adhered to in research (Bogdan & Biklen, 2007; Glesne, 2011; Patton, 2002; Seidman, 2013). Upon receipt of approval in September 2016 (see *Appendix A*), I began contacting potential research participants outside of school hours, off and away from school and board property, either in person, by telephone, or by email.

Ethical Considerations

As my study involved conducting research with human participants, I addressed the following ethical considerations during my study: informed consent, withdrawal, security, confidentiality, anonymity, compensation, deception, risk, benefits to participants, benefits to society, as well as issues of ethics and bias (Glesne, 2011; Kvale & Brinkmann, 2009; Merriam, 2009; Patton, 2002; Seidman, 2013). Ethical considerations were addressed therein to protect my research participants, me as researcher, my supervisor, Dr. Heather Rintoul, Nipissing University, and the doctoral committee members who graciously agreed to help guide my study.

Informed Consent

Prior to beginning each individual interview, I provided each participant with two complete, clean copies of their group-specific Participant Information Letter and Consent Form. I explained to each participant the purpose of my study and reviewed the document section by section and answered any and all participant questions at that time. In the case of minor children/teen participants, I required the written and informed consent of the parent (which included two signed copies of the Participant Information Letter and Consent Form for Parents of Minor Children/Teens) and obtained the written and informed "assent" of the child (Seidman, 2013, p. 76). All participants were asked to sign two copies of the consent form—one for me as researcher and one for their personal files.

Withdrawal

All participants were made aware in the initial contact conversation and in their preinterview conversation that their participation in my research study was voluntary and they may at any time: (a) choose to withdraw from the study before its completion without any penalty whatsoever (Seidman, 2013); (b) refuse to answer any question and remain in the study (Seidman, 2013); or, (c) change or omit responses on the transcript during the member checking process if they "disclose information they may later regret having shared" (Kvale & Brinkmann, 2009, p. 73).

Security

As a researcher, security refers to the processes I employed to keep data safe when it was not in use (Seidman, 2013). I personally contacted, interviewed, audio-recorded, and fully transcribed each interview myself (Merriam, 1998, 2009; see also Glesne, 2011; Kvale & Brinkmann, 2009; Seidman, 2013). With the exception of my daughter, Ashley, who wanted her actual name used in my dissertation, I used a coding system known only to me and used pseudonyms in my study instead of real names to protect the identities of my participants (Seidman, 2013). When interview recordings or transcripts were not in use, I ensured all consent forms, audio-recordings, USB sticks, transcripts, and field notes were secured in a double combination-locked location in my home (Seidman, 2006, 2013). I was the only person to access my data, although my supervisor, Dr. Rintoul, could have accessed my data if she so required it.

Confidentiality

I explained to the research participants that with respect to confidentiality, I can and will guarantee the confidentiality of the information they share with me during their interviews; however; certain words and phrases may be quoted directly in the dissertation (Seidman, 2013). It should be noted that confidentiality in this regard does allow for the sharing of the research data collected during the one-on-one in-depth interviews (Seidman, 2013). Quoted words and phrases may be/will be attributed directly to my daughter. Regarding all other study participants, someone who knows a participant *and* knows that s/he participated in my study, may perceive a

participant's identity through the words used in a direct quotation (Merriam, 1998; Seidman, 2013). All participant consent forms, contact numbers or email addresses I collected during the research study were kept in a locked, secure location in my home, accessible only to me (Seidman, 2013).

Anonymity

During my research study, every effort was made to protect the identity of the participants (with the exception of Ashley whose actual name is used). As such, I was the only researcher to contact participants, conduct interviews, and handle participants' data. I carefully selected pseudonyms and made use of contextually relevant non-identifying terms such as "the principal" and "the school" in order to further protect the identity of individual participants and any person who was named during a participant's interview. While these measures were taken, it is important to note that anonymity cannot fully be guaranteed, as someone who knows an individual participant and that s/he participated in my study may be able to attribute a quotation to her/him and subsequently perceive an individual's identity (Seidman, 2013). For example, a parent who was not a participant in the research study may, upon reading the study, recognize a particular turn of phrase that her/his participating child or teen frequently uses and could correctly ascribe the phrase to her/him on the comparison of the phrase to her/him on the comparison of the phrase to her/him on ther phrase to her/him on the phrase to her/him on the phrase

Compensation

Participants were informed that they would not be compensated either financially, inkind, or in any other way for their participation in my research study. All interview participants received a handwritten thank you card in appreciation of their contribution to my research study at the time their transcript was delivered to them for review.

Deception

I did not deceive participants at any time during the research study process.

Potential Risks to Participants

I do not foresee any possible risks to participants greater than those a participant may encounter in everyday life. To clarify further: (a) I do not anticipate any social or economic risks or harm will come to any of the participants in the study; (b) my research study did not involve any physical risks or harm, linkages to instruments, administration of drugs, or confirmatory allergen testing; (c) my study did not take place in dangerous location such as a war-torn country; and (d) my study did not involve any linguistic or cultural sensitivities (Seidman, 2013).

My study procedures did not include physical contact of any kind. While I had initially anticipated a handshake might be used as a salutation at the beginning of an interview or as a thank you the end of an interview, in the moment, the gesture seemed too formal and somewhat contrary to the relaxed atmosphere that I had tried to create and maintain during the individual interviews. Further, I did not want an interview participant to be worried that I had come into contact with one of their offending allergens or be uncomfortable declining a handshake offered as a gesture of courtesy (Kvale & Brinkmann, 2009; Seidman, 2013).

In order to address the ethical principle of beneficence or least harm, I feel it important to state that when I met with a child who has food allergies or their parent, I took extra care *not* to consume or use products containing their offending allergen(s) on the day of the interview (Kvale & Brinkmann, 2009). Likewise, I washed my hands before leaving home as an extra measure of care. I brought with me to the child/teen interviews, new pens in a sealed package

for participants to use when signing consent forms. I felt that this act of care might serve to put participants at ease and further reduce the likelihood of an accidental allergen exposure.

While I did not anticipate any psychological risks and/or harm to come to the interview participants during the research process, as the parent of a child with food allergies and a researcher, I did acknowledge that there was a chance that a child or parent may choose not to answer, or have difficulty answering, possible interview questions (Seidman, 2013). In one instance a mother's eyes did tear up when recalling one of her daughter's early allergic reactions. When that happened I retrieved the nearby the box tissues, asked her if she was okay to continue, and then waited patiently for a response. Additionally, I did remind the mother that she did not have to continue; however, after a moment, she proceeded with her story.

While I did not anticipate my open-ended questions posed a risk of harm to participants, individuals may reflect on their interview and have questions about food allergies or anaphylaxis that they had not previously considered. To address this possibility, I included in each of the group specific Participant Information Letter and Consent Forms a prepared list of allergy and anaphylaxis agency contacts, including, where applicable, both websites and phone numbers for further support (Seidman, 2013). I added a disclaimer on the reference list informing participants that the "resource list is for information purposes only" and if they are "experiencing an emergency" that they should seek appropriate medical advice.

Issues of Ethics and Bias

As addressed earlier in *I Situate Myself in the Study*, my life experiences and worldview have informed my study purpose and research questions. Here, I remind readers that I have interpreted the participant experiences through my own researcher lens. I acknowledge my research perspective has not only influenced my topic, participant selection, as well as data

interpretation and analysis, but also the manner in which I, as researcher, have ultimately chosen to *present* the participants' perceptions and meanings in my study (Merriam, 1998; Seidman, 2013). I am aware that if everything else in the study remained the same, and only the researcher changed, another researcher's findings may be different from mine (Glesne, 2006, 2011).

Participant Sample

In this section, I provide an overview of my sampling technique. Then, I outline the criteria I used to select potential interview participants from each of the four participant groups.

Purposive Sample of Convenience

I used a purposive sample of convenience to select participants for all four participant groupings in my study. The intent of the purposive sample is for the researcher to select a sample "from which the most can be learned" (Merriam, 1998, p. 61; see also Erlandson, Harris, Skipper, & Allen, 1993; Seidman, 2013). I believe convenience sampling aligns with my research topic as I wanted to select potential participants not only because they were interested, willing, and available to participate in my study but also because they potentially had relevant "information-rich" allergy-related life experiences from which to draw (Gall, Gall, & Borg, 2005, p. 310). I believe the private, health-sensitive nature of my study topic required that I select potential participants from my personal and/or professional contacts instead of using public recruiting techniques as the researcher-participant *relationship* is a key aspect of qualitative research (Glesne, 2011; Kvale & Brinkmann, 2009). To clarify, I first considered adults who I knew either to be: (a) parents of children who have food allergies, or (b) Ontario educators. Potential participant-researcher familiarity varied greatly. I feel it important to mention that with the exception of my daughter, I did not and do not have daily contact with or hold supervisory responsibilities over any of my potential study participants (Seidman, 2013).

Further, while the prevalence of food allergies is on the rise (George & McQuaid, 2010; Gruchalla & Sampson, 2015; Hay et al., 2006; McIntyre, Sheetz, Carroll, & Young, 2005; H. Sampson, 2003; Shemesh et al., 2013), it has been my experience as the mother of a child with food allergies and as an educator, that the *actual* number of children/teens (and families) in any given school or community is relatively small. In adherence with the ethical requirements of my Nipissing University Research Ethics Board protocol, I have taken care not to describe in too much detail how I know or have come to know any potential study participants as I believe that doing so may risk revealing a participant's identity (Bogdan & Biklen, 2007; Glesne, 2011; Kvale & Brinkmann, 2009; Seidman, 2013).

Sample Selection Criteria for Interview Participants

As I was interested in the school experiences of children/teens with food allergies as perceived by parents, teachers, school administrators, and the children/teens with food allergies themselves, I required my research participants to fulfill the necessary criteria as addressed for each participant grouping in the subsections below (Merriam, 1998). I was able to ascertain if potential participants met my criteria from the information provided during a brief conversation (in person, by telephone, or by email) conducted off and away from school/board property and outside of school hours. I accepted in my study the first participants who met my study criteria as detailed for each participant group below (ultimately these were all female, save one).

Children and/or teens. Potential children or teen participants in my study were required to have a food allergy (requiring prescription epinephrine) and have current or previous experience attending school. To offer a little different, more personal perspective perhaps than my other study participants, I interviewed my own daughter. It was my intent to interview children/teens aged 12–19 to participate in my study. There are several reasons why I feel the

12–19 age range was most appropriate for my study around the school experiences of children/teens with life-threatening food-induced allergies, including research that suggests:

- The highest incidence of food-induced anaphylaxis occurs between ages 0–19 (Canadian Society of Allergy and Clinical Immunology, 2014).
- Some transfer of responsibility from parent to child typically occurs between ages 12 and 14 (M. Sampson et al., 2006; Sicherer, 2013; Young, Muñoz-Furlong, & Sicherer, 2009).
- Adolescents are at a higher risk of fatal food-induced anaphylaxis occurring at school (George & McQuaid, 2010; Hay et al., 2006; McIntyre et al., 2005; Sheetz et al., 2004).
- 4. There are potentially more opportunities for students aged 12–19 to experience increased autonomy and responsibility as they transition from elementary to secondary school (or to a postsecondary school in the case of older teen participants).

It was my original intent to interview a minimum of three and a maximum of five children/teens of varying ages, genders, and food allergies. I realized early on in the sample selection process that my personal contacts included more female teens with food allergies than male teens with food allergies—gender was no longer an "essential" criterion but rather an aspect of convenience (Merriam, 1998, p. 61). I decided that if it happened that the first five potential participants satisfied the essential selection criteria, they would be accepted as participants. Using the principle of theoretical sufficiency (Marshall & Rossman, 2011) or saturation as my guide (Eisenhardt, 2002; Johnston & Christensen, 2012), I stopped interviewing new participants when I felt that clear patterns in my data emerged that would allow me to answer my research questions (Erlandson et al., 1993; Merriam, 2009).

Parents. I intended to interview two or three parents who have children with lifethreatening food-induced allergies and anaphylaxis. Potential participants satisfying the parent grouping criteria needed to satisfy the following criteria:

- be the biological/adoptive/step-parents, parents, or legal guardians of a child/teen with food allergies (requiring prescription epinephrine); and
- be the parents/legal guardians of a child/teen who is currently attending or has attended school in the past.

I acknowledge that while my study criteria did exclude parents of babies and toddlers with food allergies (as these children do not attend school and my study focuses on the school experiences of children/teens), the parent participants in my study were welcomed to discuss their child/teen's early years during their interview if they wished. While it was my preference to interview both mothers and fathers of children with food allergies, I recognized that this might not be possible due to parental interest, response (Rouf et al., 2011), availability, or family composition. I decided that if it happened that the first three potential participants satisfied my selection criteria, they would be accepted as participants. I had already completed interviews with two mothers and a father when a third mother's unique experience came to light during an initial conversation about the possibility of her daughter participating in my study. I felt this mother was an "information-rich" source that would enhance my study and, as such, I invited her to participate in an in-depth audio-recorded interview (Patton, 2002, p. 46; see also Gall et. al., 2005).

Teachers. It was my intent to interview up to a maximum of three teachers, and I hoped that my participant sample would include both male and female teachers of varying ages and years of experience. Potential teacher participants were required to:

1. be certified by the Ontario College of Teachers to teach in Ontario, and

2. be currently practicing as a teaching professional in the province of Ontario as an elementary or secondary supply teacher/occasional/permanent teacher.

Although I did not deem it an essential criterion, preference was given to teachers who have had a child/teen with food allergies (requiring prescription epinephrine) as a student in their class. If it happened that the first three potential participants satisfied the selection criteria, they were accepted as participants—two female teachers, one elementary and one secondary, agreed to participate in my study.

Administrator(s). I intended to recruit one or two school administrators of varying ages, genders, and years of experience. Potential administrator participants were required to:

- 1. be certified by the Ontario College of Teachers to teach in Ontario;
- have current or previous experience as a permanent or acting vice-principal, principal, supervisory officer, or director of education in a public, private, or otherwise identified school setting; and
- have experience having children with food allergies (requiring prescription epinephrine) in their schools.

In the sample selection process, attention was given to drawing on a wide range of experiences "from which the most can be learned" (Merriam, 1998, p. 61). Two administrators satisfied the selection criteria and were accepted as participants; however one of the administrators experienced a personal situation on the evening of the scheduled interview and was unable to commit to another time, despite a genuine interest in and consenting to participate in my study.

Invitation to Participate in an Interview

I made initial contact with individuals in my personal and professional networks off and away from school or board property and outside of school hours via personal telephone or my personal email (Seidman, 2013). During the brief introductory telephone conversations or emails (where email was my only known method of contact), I introduced myself, explained the purpose of my research study, and asked if the individual would be interested in reviewing a Participant Information Letter and Consent Form about my study. In the case of potential minor children/teen participants, I asked the parents to also review the Participant Information Letter and Consent Form for Parents of Minor Children/Teens (Seidman, 2013). Initial conversations lasted anywhere from 10 minutes to 25 minutes depending on researcher-potential participant familiarity and the questions that participants/parents of potential minor participants had. At no time during any initial conversations did I ask potential participants for a commitment to participate in my study—instead, I viewed the initial contact as an opportunity to set up a time to deliver the Participant Information Letter and Consent Form (Seidman, 2006, 2013). In many instances, I hand-delivered the individual Participant Information Letter and Consent Forms and, where travel/distance was a factor, I used my personal email. I made a follow-up call or email within 3 to 7 days after delivery of the Participant Information Letter and Consent Forms to confirm potential participant interest in my study, answer any questions, and arrange a time for the interview to take place (Seidman, 2006, 2013). In two instances, I left a phone message and call-back number for the potential participants to return my call. During follow-up communications, four adult study participants provided me with their personal cell phone numbers and one potential adult study participant provided a home phone number (to be used instead of email). When speaking with the parents of potential minor study participants, it became clear to me that the parents had spent time reviewing the Participant Information Letter and Consent Forms with their respective children, as during the follow-up call the parents reported their children's willingness to participate in my study. I feel it important to note that at

no time during the research study process did I request or acquire the personal cell phone numbers of the two minor participants (who are not my children). Likewise, I did not communicate with the two minor participants without their parents' knowledge or consent.

Interview Participants: Introductory Profiles

Over a 3 and a half month period from September to December 2016, I interviewed three children/teens, four parents, two teachers, and one school administrator around their perceptions of the school experiences of students with life-threatening food-induced allergies and anaphylaxis. Each of the 10 individuals who agreed to participate in an audio-recorded in-depth interview was selected according to the aforementioned criteria (see *Sample Selection Criteria for Interview Participants* earlier in this chapter). At the time of the interviews, all study participants were residents of Ontario, Canada. The participants' experiences reflect their personal dealings with or in English public or English Catholic school board(s) of education.

In this section of the chapter, I use subheadings to delineate each of the four groups of interview participants and provide a general description of the participants as a collective. Following each group description, I share a brief introductory profile of the individual interview participants in order to help the reader better navigate the interpretation and analysis portion of the dissertation which follows in Chapter Four. I feel it important to note that with the exception of my daughter Ashley (by her request and approved by the Nipissing University Research Ethics Board), I use pseudonyms to protect the anonymity of each participant (Seidman, 2013).

Children/Teens

Three females, ages 12 to 16, agreed to participate in my research study around the school experiences of students with life-threatening food-induced allergies and anaphylaxis. At the time of their respective interviews, all three minor participants lived at home with both

parents and their sibling(s) and were students attending school. All three young women have allergies to, and prescription epinephrine and antihistamines for, one or more of the foods identified by Health Canada as priority allergens (Government of Canada, 2015; see also Gold et. al., 2003). All three minor participants: (a) were the firstborn children of their mothers; (b) experienced natural births; (c) have fathers with a confirmed allergy/sensitivity to one or more priority allergens; (d) were breast-fed by their mothers (who had restricted diets during breastfeeding); (e) had atopic tendencies as infants (eczema, gastrointestinal pain, bloody stool); (f) are allergic to nut products and avoid one or more fresh fruit(s); (g) have had allergic reactions at school; and (h) have felt excluded at school because of their allergies. Two of the three participants: (a) were born in the fall; (b) have had allergic reactions to milk, eggs, and wheat; (c) have a dog as a family pet; (d) have been teased about or because of their allergies; and (e) are concerned about moving away from home to attend postsecondary school.

Ashley. My daughter Ashley is a 16-year-old grade 11 student who has confirmed food allergies to: hazelnuts, cashews, peanuts, almonds, pistachios, walnuts, apples, pears, strawberries, and cherries. She carries epinephrine for her nut allergies. As well, Ashley consistently experiences oral allergy syndrome when she eats: raw carrots, cantaloupe, cherries, peaches, nectarines, and plums—so she avoids these foods. At times, she has symptoms of oral allergy syndrome when she consumes cucumbers, celery, kiwi, honeydew melon, and watermelon. Although Ashley can eat cooked potatoes, she develops hives on her hands if she touches them in their raw state. Ashley's aeroallergens include: birch, oak, tree mix, grass mix, ragweed, willow, and ash trees as well as cats and horses. Ashley has seemingly outgrown asthma but continues to be troubled by eczema on her hands. Ashley's father has developed an adult-onset food reaction to shrimp and lobster that includes swelling of the throat and eyes.

Megan. Megan is a 15-year-old grade 10 student who carries epinephrine for her confirmed allergies to milk, eggs, and all nuts (airborne to peanuts). When she was younger, Megan was allergic to sesame seeds and wheat but has since tried sesame and has undergone an oral food challenge with positive results—she is no longer allergic to these foods. Peaches "are a problem" for Megan, and she also avoids mango as she has been told it is "related to the nut family." In addition to her food allergies, Megan also has asthma and eczema. She is the firstborn child of Diane and Grant (see *Parents* below), who have asthma and a pistachio allergy respectively. Megan has two younger siblings who have mild asthma but no food allergies.

Robyn. Robyn is a 12-year-old grade 7 student who is allergic to eggs, milk, soy, wheat, lentils, peas, chickpeas, nuts, and bananas. Robyn experiences oral allergy syndrome when she eats some fresh fruits and vegetables like raw carrots, pineapple, and apples (although she can tolerate Macintosh apples) and therefore avoids these foods. "Depending on the season" Robyn is also troubled by cucumbers, tomatoes, and lettuce. As a baby, Robyn had eczema that has since cleared when offending foods were removed from her diet. She was diagnosed as having asthma around age 7 but was previously asymptomatic. In addition, Robyn developed an allergy to the antihistamine Benadryl® and believes it is because she "took it so much" when younger. Robyn is allergic to horses, some dog breeds, and has recently developed an allergy to cats which she feels she is the "only" allergy she is "going to outgrow" someday. Robyn is the firstborn child of Barb (see subsection *Parents* below) and has a younger full-sibling who does not have food allergies. Robyn's father and her step-siblings have food sensitivities.

Parents

Three mothers and one father agreed to participate in my research study. At the time of the interviews, three of the four parent participants were employed outside of the home in part-

time or full-time jobs. Megan's parents, Diane and Grant, are the only parent couple who were both interviewed. Robyn's parents decided that her mother, Barb, would be interviewed. Kim is the only parent who participated in my study who did not also have a child in my study.

Barb. Barb is the biological mother of two children and step-mother of two others. Barb's firstborn biological child, Robyn, has food allergies (see *Children/Teens* above). Barb's spouse and step-children have known food sensitivities. Barb does not have food allergies, although her father was "apparently . . . allergic to milk when he was a baby" however Barb did not know this until Robyn was 6 years old. Barb's nephew has outgrown his milk allergy.

Diane. Diane is Megan's biological mother, the mother to two other children, and is married to Grant (see subsection below). Diane has asthma and eczema but does not have food allergies. Diane and Grant's two youngest children have mild asthma but do not have any known food allergies.

Grant. Grant is Megan's biological father, the father to two other younger children, and is married to Diane (see previous paragraph). Although Grant does have pistachio allergy, it was only mentioned by Diane in passing (and later confirmed during the transcript review process) as something they "just don't really talk about" or address. Grant's mother has a raw egg skin contact allergy and carries epinephrine for her shrimp allergy. Grant's nephew has a nut allergy.

Kim. Kim is the mother of two children—only one of whom, her eldest child, a 19-yearold son, developed a peanut allergy at age 6. Sunflower seeds and coconut were identified as offending allergens when her son was in high school. Kim noted that her son's MedicAlert® bracelet also says penicillin because "once he had penicillin and got a rash," so he avoids it. Kim is allergic to penicillin and her spouse is allergic to cats.

Teachers

Two experienced classroom teachers agreed to participate in my research study. While I originally intended to interview teachers of students aged 12–19, after interviewing two parents (from different families), it became clear that my study would be greatly enhanced if I included an elementary educator with primary division experience as well as a secondary educator. When inviting the teachers to participate in an interview, I was aware only that both educators had previously taught students with food allergies and that Tina avoided peanut products.

Angela. Angela has been an educator for 25 years and is currently employed as a teacher in the elementary panel. Angela has "been told [she's] allergic to whitefish but [she has] never had a reaction to it" so doesn't "really worry about it." Although Angela does not currently have students in her class with food allergies, she has in the past had students in her class with nut allergies. Within the schools where Angela has taught there have been students with lifethreatening allergies to milk, citrus, and plum sauce. Angela is the only participant in my study to have administered an epinephrine auto-injector (although for a nonfood allergy to scents).

Tina. In education for 18 years, Tina is currently employed as a secondary school teacher. Tina developed a late onset peanut allergy in her early 20s that bothers her when she accidentally ingests something with peanut in it. As well, she avoids latex products, honeydew melon because her "voice goes," and kiwi because it makes her throat "scratchy." Tina's sister has a shellfish allergy, but no one else in her family has food allergies. Currently Tina has one student in her class who carries prescription epinephrine for a latex allergy but has previously had students in her class with nut allergies.

Administrator

Only one educator with experience as a school administrator agreed to and was able to participate in my research study.

Carolyn. In education for 30 years, Carolyn has experience at both the elementary and secondary levels. As well, Carolyn has taught Additional Qualifications courses for teachers and has worked to write curriculum support documents for the Ontario Ministry of Education. Carolyn has just under 3 years' experience as an elementary school administrator. Carolyn does not have any food allergies, nor do any of her immediate family members. Carolyn is the only educator in my study to have accompanied a student to the hospital after epinephrine was administered at school for an allergic reaction (to nuts).

Interview Settings

The health-sensitive nature of my research required careful consideration of the interview setting, particularly for those individuals and families affected by life-threatening food allergies. As detailed in my Nipissing University Research Ethics Board protocol, all interviews were conducted off and away from school or board property and outside of school hours. All participants who agreed to be interviewed were asked to determine a mutually convenient allergen-safe quiet location (off and away from school or board property) and suggest a time that suited their personal and familial schedules. In the case of an interview with a minor participant, I required a parent to be present in the interview location for the comfort and safety of both the child/teen participant and myself. I did respectfully request that the accompanying parent not be present in the interview room as the child/teen's responses may differ if the parent were to stay in the room. Similarly, I requested that children (who were to be interviewed) not stay in the room during a parent interview for the same reason.

I felt strongly about accommodating the suggested interview location and time requests as I believe a "naturalistic" environment provides a "context" where participant "action can best be understood" (Bogdan & Biklen, 2007, p. 4; see also Mason, 2002). While the school may seem to be a natural setting for educator interviews to occur, I am aware that behaviour is "significantly influenced by the setting in which it occurs" (Bogdan & Biklen, 2007, p. 5). As such, it is my view that educators may be more likely to access a more authentic inner voice (Steiner, 1978) if interviews are conducted off and away from school or board property.

It is my view that an "allergen-free" location would provide individuals and/or their family members a more relaxed, secure setting that would minimize participant risk, concern, and/or possible safety distractions. In order to protect the research participants and/or their family members from harm, on each interview day, as an extra measure of care, I avoided contaminating the interview space by not consuming any of the participant's offending allergen(s) or using products containing the participant's offending allergen(s); (Bogdan & Biklen, 2007; Kvale & Brinkmann, 2009). Additionally, during all interviews, I refrained from wearing scented lotions, perfumes, or hairsprays that could trigger a possible allergic response.

All interviews took place in the kitchen or in living rooms of homes either on weekday evenings after 5:45 p.m. or on weekends. Half of the participants requested their interviews take place in their own homes; one interview took place at the home of a participant's relative; two interviews occurred at my home; and three others took place at another mutually agreed upon location. I found it interesting that the only interview to take place in a kitchen was the longest of all interviews. When reviewing my descriptive and reflective notes, I wondered if the kitchen was the place where the mother felt most in control or most at ease speaking of her child's food allergies, or if it was simply a matter of convenience as other family members were occupying

other rooms. A review of this mom's transcript revealed the last quarter of her interview focused on her concern for her child's social well-being. In particular, she discussed challenges to socialization and allergy supports that have resulted in positive experiences for her family. I wondered if the interview length coincided with a feeling of rapport or trust that developed as the interview progressed or if it was because the setting was comfortable (Seidman 2006, 2013).

Data Collection

My primary strategy for data collection was the use of one-on-one individual in-depth audio-recorded interviews supported by the use of a researcher field journal that included both descriptive and reflective notes (Glesne, 2011; Kvale & Brinkmann, 2009; Merriam, 2009; Seidman, 2013). Here, I explain how data collection methods align with my research questions.

One-On-One Interviews

My main strategy for data collection was one-on-one in-depth audio-recorded interviews of approximately 45 minutes in length for children/teens and approximately one hour in length for parents, teachers, and administrators, around their perceptions of the school experiences of students with food allergies and anaphylaxis (Seidman, 2013; see also Glesne, 2011; Kvale & Brinkmann, 2009). By using personal interviews as a method of inquiry I hoped to better understand the lived experiences of participants and their individually ascribed meanings of their experiences (Seidman, 2013). While it was my original intent to complete the child/teen and parent interviews before beginning any educator interviews as I anticipated the familial interviews may better "inform" the educator interviews (Seidman, 2013, p. 116), this was not what actually happened. I had hoped that by completing the interviews with the minor participants and parents that they might bring up a school-related allergy concern that I had not previously considered and I would perhaps be able to incorporate the issue into a future teacher or administrator interview. In reality, participant availability determined the order of interviews.

General Schedules of Interview Questions (GSIQ)

I created five General Schedules of Interview Questions (GSIQ), one for each group of children, teens, parents, teachers, and administrators (Appendices B, C, D, E, and F) based on an extensive review of literature and on my own experience as a parent of a child with food allergies and as an educator (Pitchforth et al., 2011). It is important to note that while I have four participant groupings (children/teens, parents, teachers, and administrators) in my study, I felt it necessary to create two separate General Schedules of Interview Questions—one for children and one for teens-that use age-appropriate language. The General Schedules of Interview Questions were used as tools to ensure that I collected comparable data between and among participants from the four groups (Bogdan & Biklen, 2007). The intent in using a General Schedule is to provide a "basic structure" and "focus" for each interview (Seidman, 2013, p. 94). As each interview is really an "inter view" that is conversational in nature, the General Schedules of Interview Questions were not provided to participants previously, nor at the time of the interview, to ensure that responses were in no way rehearsed (Kvale & Brinkmann, 2009, p. 2; see also Patton, 2002). I used the few open-ended questions on each General Schedule of Interview Questions as a guide to begin the interview. I feel that the open strategy did allow for conversation to flow so that each participant's "unique experiences, special stories," understandings, and perceptions could be shared (Stake, 1995, p. 65; see also Glesne, 2011; Seidman, 2013). The open strategy allowed me to follow unexpected leads (Glesne, 2011) and explore deeper understandings through the use of clarifying questions (Seidman, 2013). I paid particular attention to, and noted in my researcher field journal, participants' body language,

posture, eye contact, facial expressions, emotions, vocal intonation, laughter, whispers, pauses, silence, and word choice during the individual interviews and used these as cues to guide my next researcher steps (Merriam, 1998; Seidman 2006, 2013). I felt that the open strategy allowed me to deviate from the prepared General Schedules of Interview Questions in order to follow the individual participants' leads, to areas that were of interest to them, which was important as it was the participants' perceptions I sought.

Five General Schedules of Interview Questions Explained

The General Schedule of Interview Questions for Children (Appendix B) is comprised of: five questions to confirm the child's allergy/establish a context (Seidman, 2013), and put the participant at ease (Patton, 2002), three questions about daily family life, and four questions about the child's allergy-related school experiences. In addition, there is an individual perception question about the best and most difficult thing about being a student with food allergies. A final open-ended question on each of the General Schedules asks if there is anything else the participant would like to add. The General Schedule of Interview Questions for Teens (Appendix C) follows the exact same line of questioning as the General Schedule for of Interview Questions for Children but at times uses more complex vocabulary. One example, instead of asking the children "What do you or your family members do to keep you safe at home?" the teens were asked a similar but slightly more complex question "What supports/ strategies are in place in your home to keep you safe?"

The General Schedule of Interview Questions for Parents (Appendix D), has one prompt statement and one question that were used to confirm the individual parent participant's experience with allergy. Although the statement and question were open ended, I anticipated that parents might seek clarification, so the actual copy of the General Schedule does have additional word prompts and phrases that I was able to use if required. Four questions ask about daily life as the parent of a child with food allergies and one question asks about involvement with the school. Similar to the General Schedules for Children and Teens, parents were asked about perceived challenges and positive aspects of parenting a child with a food allergy. The last question on the General Schedule of Interview Questions for Parents is an open-ended question that provides parents the opportunity to share further insights, thoughts, feelings, or suggestions.

Appendices E and F are the General Schedule of Interview Questions for Teachers and the General Schedule of Interview Questions for Administrators respectively. They are similar in that they both have: one experiential/context setting prompt to put the participant at ease (Patton, 2002); one question about daily classroom/school decision-making; one role-specific question about challenges; and two perceptual questions about student allergy challenges/ positive aspects and student learning. The last question on both the General Schedules of Interview Questions for Teachers and Administrators is an open-ended invitation for the teachers and administrators to address anything about the research topic they had not been given the "opportunity to discuss" in the previous questions.

Audio-Recording

I used two audio-recording devices to record each individual one-on-one interview so that I would have a full and complete original account of each participant's stories, experiences, perceptions, and meanings in her/his own words (Seidman, 2013). A previous unrelated research experience where I lost participant data informed my decision to use two recording devices to ensure that I would not lose access to any participant data. As a qualitative researcher, I was attuned to the vocabulary that participants used, as I feel language is intimately connected to and reflective of thoughts, values, and behaviours (Vygotsky, 1934/2012; see also Monteath & Cooper, 1997). Audio-recordings of each individual interview allowed me to: create a written transcript of the interview, confirm with each participant the accuracy and intended meaning of her or his interview data, and avoid imposing my own researcher voice on the participant experiences (Seidman, 2013). Additionally, individual audio-recordings (and the respective transcripts) have served as researcher/organizational tools during data collection, interpretation, and analyses processes to: (a) assure participants that I value their responses; (b) allow me to focus on capturing the essence of the interview rather than a summary of participant's words; (c) ensure I have attributed certain quotations or ideas to the correct participant; and (d) confirm a thought or feeling I have about the participant's meaning by listening to the recording another time (Kvale & Brinkmann, 2009; Seidman, 2013).

Field Journal Considerations

As interviews are "live social interaction[s]," I kept a field journal throughout the data collection process in order to record *descriptive* and *reflective* notes (Kvale & Brinkmann, 2009, p. 178; Merriam, 2009). Prior to each interview, I informed participants that I would be making descriptive notes to record my observations of the interview setting, body language, facial expressions, or other physical reactions that are not easily perceived by the audio-recording (Bogdan & Biklen, 2007; Glesne, 2006; Merriam, 2009). For example, a participant may say something but her/his tone of voice and body language may support an opposite or sarcastic meaning that is different from what the words alone may communicate. Similarly, I made reflective notes during each interview to capture my thoughts, feelings, or initial interpretations about the meaning of the experience (Bogdan & Biklen, 2007; Glesne, 2006; Mason, 2002; Merriam, 2009; Patton 2002). Additionally, I used my field journal to support my interpretations and as part of my 'audit trail' so that I could improve the consistency and dependability of my
interpretation of my participants' data (Lincoln & Guba, 1985; see also Erlandson et al., 1993; Merriam, 2009). By detailing my research processes at every stage of the research journey, I feel I have increased the trustworthiness of my study (Erlandson et al., 1993; Lincoln & Guba, 1985).

Descriptive notes. I made descriptive notes during each of the individual participants' audio-recorded interviews to record things that seemed important or were of interest to me in the moment. While the focus of my notes varied significantly by individual, some descriptions included: (a) my observations of the interview setting including the room where the interview took place, participant proximity to me, and the other individuals who were in or near the interview location (Glesne, 2011); (b) my observations of the participant's body language including eye contact, facial expressions, and vocal intonation; (c) lists of allergies, medications, symptoms, rules, and strategies specific to individuals and/or their family members; (d) words and phrases that stood out to me to be unique, a reiteration or repetition of another participant's language usage, items that I wanted to follow up on, and in many instances, direct quotes (Glesne, 2011). During all interviews, I paid careful attention to recording the exact vocabulary the participants used and believe in doing so I was trying to capture the words accurately (Glesne, 2006, 2011). It seems interesting to me that almost all of the direct quotes I recorded are related to: an individual participant/family member's allergy identity, a participant's feelings/emotions, or the language used to clarify school-based food restrictions. In one instance I attempted to draw a picture to record my observation of a participant during her description of what it was like to administer epinephrine to a student. In the moment I must have thought it important but, unfortunately, looking at the picture now, it has little meaning for me.

Reflective notes. I made reflective notes during each participant interview, after interviews, and while analyzing transcripts. During participant interviews, my reflective notes

consisted of short jot notes about my thoughts and feelings about what a participant was saying or doing. At times, I also included brief statements about hunches I had and noted questions that seemed to arise from something a participant was saying or doing (Glesne, 2006; Seidman, 2013). In one instance, the first thing I recorded was "sitting forward" as an indication of a participant's position in relation to me. I see now how carefully I observed the father's body language throughout his interview and how I was reflecting-in-action in order to make sense of his seated body position that did not seem to comfortably allow for continued eye contact (Schön, 1983, 1987). By the end of the interview, I had recorded 15 instances where dad did make eye contact with me. My speculative note "honest" beside the third instance offers an explanation to the pattern—his direct eye contact revealed his ethical self (Starratt, 1994) when he acknowledged his own uncertainty ("I don't think I did"), shared his true feelings about how allergies affect his daughter ("burden"), and demonstrated empathy for his daughter ("feel bad").

The reflective notes that I made following the individual interviews tended to be longer written pieces, similar in structure to a personal journal entry. In all instances, I recalled the participant stories that most strongly resonated with me, commented on key words and phrases I wanted to explore further, and noted possible thematic connections that seemed to exist between and among the participant interviews. In autobiographical notes I reflected on moments where I was touched by the emotion that parents displayed and times when I saw similarities to my own family's allergy experience (Glesne, 2006). I also wrote about the tension I felt when I heard educators talking about what is actually happening in schools—I struggled to reconcile some of the practices they reported with the legal requirements under *Sabrina's Law*. I reflected on my feelings about the grassroots parent volunteer group that was in charge of confidential student allergy information in one school and wondered if this still exists. I see now that I also explored

a hunch that I had about a parent who I thought might be holding back about her child's wellbeing (Seidman, 2013). She used the term "anxiety" as her eyes welled up with tears, stopped midsentence and directed the conversation away from the topic, eventually coming back around to discuss her concerns about her child's socialization. I thought about this conversation turn, and return, as providing a glimpse into something this mom might have felt too private to share with an outsider—I wrote briefly about mothers as gatekeepers, protectors . . . myself included.

Transcription of Interviews

After each individual interview, I carefully and fully transcribed each verbal and nonverbal signal using Microsoft® Word (Seidman, 2013). I felt that by completing my own transcriptions, I would familiarize myself with the data and come to better understand the nuances in my participants' contributions and would also begin to make preliminary connections between and among participants as I transcribed (Seidman, 2013). I then reviewed each interview transcription in its entirety, listening to the audio-recording and reviewing the typed transcript to ensure accuracy. When transcripts were completed, I contacted each individual participant by her/his preferred method of communication to make arrangements to deliver her/his completed transcript and a handwritten thank you card. I asked each individual participant to review her/his own transcript to review for accuracy and intended meaning (Seidman, 2013). I asked that participants contact me with their amendments and indicated that if I had not heard from them that I would contact them in approximately one week to confirm that the transcript expressed their intended meaning. Seven of the 10 participants requested minor changes be made to their original transcripts. The amendments involved: (a) the substitution or addition of a clarifying word, phrase, or punctuation mark; (b) the omission of signal words like "um" or the replacement of harsh vocabulary (profanities) with lighter terms;

and (c) explanatory notes to justify the participant's request for changes. All changes were made within one week and participants were asked if they wanted a new, clean copy of their revised transcripts to once again review—none of the seven participants wanted to review the revised transcript a second time.

Validity

Although I addressed issues of validity throughout this chapter, considerations specific to my research have a collective strength worth noting. *Internal validity* has been addressed in my study design and implementation as follows: (a) acquiring Research Ethics Board approval (Merriam, 1998); (b) requiring assent and informed, written consent (Seidman, 2013); (c) triangulating data collection through interviews with multiple participants (Glesne, 2011; Merriam, 1998); (d) being the only researcher to collect, transcribe, interpret, and analyze data (Seidman, 2013); (e) asking each study participant to review her/his transcript for accuracy and intended meaning (Seidman, 2013); (f) keeping a field journal as part of my audit trail to help ensure accuracy of my interpretations (Bogdan & Biklen, 2007; Glesne, 2006; Lincoln & Guba, 1985; Merriam, 2009; Patton, 2002); (g) listening to the recorded interviews, and reviewing transcripts and field notes, multiple times, in order to ensure accuracy of the emergent themes (Creswell, 2008); and (h) revealing researcher bias by situating myself in the study (Denzin & Lincoln, 2005; Rothe, 1994). I have improved the stability of my study by interviewing more than one child, parent, and educator (Miles & Huberman, 1994). My study design addresses *external validity* by describing my participants' experiences in context as they see themselves through the use of thick or rich descriptions (Glesne, 2011; Kvale & Brinkmann, 2009; Merriam, 1998; Patton, 2002). I have contextualized, not generalized my data in order to more accurately

share detailed descriptions of participants' emic perceptions of the school experiences of students with life-threatening food allergies (Kvale & Brinkmann, 2009; Mason, 2002).

Procedures: Strategies for Data Interpretation and Analysis

Data interpretation and analysis was a multistep inductive process which included: (a) within-interview, (b) within-group cross-participant interview, and (c) cross-group crossparticipant interview interpretation and analyses which I feel served to better illuminate the views of the participants in my case study of the school experiences of students with lifethreatening food allergies (Baxter & Jack, 2008; Seidman, 2013). After all transcripts were deemed accurate and complete by my participants, I began within-interview interpretation and analyses; within-group, cross-participant interpretation and analyses; as well as cross-group, cross-participant interview interpretation and analyses (Merriam, 1998). I randomly assigned a different colour font to each of the individual participants in my study so that when I handled their data I would immediately know which participant's transcript I was referring to. I felt that this strategy was essential for me to keep my data organized as I progressed. I feel it worthwhile to note that throughout data interpretation and analysis procedures, I referred to my research questions and theoretical framework to maintain focus on my study purpose (Agee, 2009; Saldaña, 2013). Here, in Chapter Three, I share my procedures; my findings, in Chapter Four. Within-Interview Interpretation and Analysis

I interpreted each individual transcript, one at a time, in its entirety as I collected the data in order to gain a sense of each document as a whole (Merriam, 1998; Saldaña, 2013). On first reading, I used an "eclectic" open-ended hand-coding process, recording my initial impressions of the data directly on the transcripts (Saldaña, 2013, p. 5). My initial thoughts and impressions included but were not limited to: words and phrases that were intriguing, concepts of interest, recurring thoughts, as well as any idea that I felt could be connected to possible themes. I marked passages that seemed noteworthy even if I was not initially sure why intuition had drawn me to the quote (Janesick, 2004; McCutcheon, 1990; Saldaña, 2013). I held those passages in mind as I read other individual transcripts, hoping to find clarity.

During a second and all subsequent readings, I used symbols, words, and phrases to capture the *essence* of the experience shared by the participant in the interview (Saldaña, 2013). At this time, I also began to use coloured highlighters to mark repeated patterns in each text. When there were multiple ideas worth noting in a single passage, I used a "simultaneous coding" process, whereby I used multilevel codes to note emergent categories, concepts, patterns, or interrelated aspects of the data (Saldaña, 2013, p. 6). Many passages were multicoded, and one piece of text was coded with four different colours and multiple words, as it seemed to me to link to many emerging thoughts. I concluded the individual transcript interpretation and analysis with a thorough line-by-line coding to increase the *trustworthiness* of the process and to ensure I did not impose my own researcher bias on the data (Charmaz, 2005, 2008). I recorded all emergent codes in my researcher codebook for later organization and categorization (Saldaña, 2013).

When I was satisfied that I had completed a detailed interpretation/analysis of an individual transcript, I spent time writing in my researcher journal, offering my thoughts about each individual transcript. At the end of each reflection, I tried to capture the overall sense or essence of the individual interview and distill my reflective thoughts down to three points of interest that seemed important in each individual participant's transcript (Saldaña, 2013). These three-point 'reflexive' analytic memos helped me to "think critically," "challenge [my] own assumptions," and allowed me to "recognize" how "thoughts, actions and decisions" affected my research perspective (Mason, 2002, p. 5; see also Rouf et al., 2011, Saldaña, 2013). For

example, I was not surprised that my own daughter had the longest interview of the children/teen participants, as our close mother–daughter rapport was pre-established (Seidman, 2006, 2013).

I repeated my within-interview coding and reflection with each individual transcript and though I found it to be very worthwhile, at times I found the sheer volume of data to be overwhelming. With 274 pages of single-spaced transcripts, I needed a strategy. At this point in my process, I decided to create and display on my workspace wall a list of the 13 tentative categories which had emerged from the 10 participant voices. I used my visual reference/list as a rudimentary organization tool that allowed me to add, expand, and connect ideas while simultaneously refining my thinking and the topics that would eventually morph into my overarching themes and subthemes. I found this visual tool was particularly helpful in allowing me to see links between data pieces that, on first glance, seemed to have no apparent relationship.

Within-Group, Cross-Participant Interview Interpretation and Analysis

As I employed a single case study design with different participant groups and different perspectives around the same issue, I needed to ensure I completed a thorough within-group, cross-participant interview interpretation and analysis. Once all individual interviews had been interpreted, I began the process of examining the participant interviews within like interview groups (Merriam, 1998). I expected at this point I would be attuned to making links back and forth between data and ideas and felt that hand-coding and highlighting would continue be the most effective way for me to look for emergent themes, identify patterns, or make connections between and among participants in the subcategory groups (Saldaña, 2013). I started the withingroup, cross-participant interview interpretation and analysis process by: skimming each of the interviews in the group, reading each of the individual reflective notes, and reviewing the three

essence points for each individual interview in the group (see *Within-Interview Interpretation and Analysis* above). So interesting to me during this phase is that where I had previously marked text based on 'intuition' in one participant's transcript, another participant's transcript seemed to illuminate or provide insight to my understanding (Janesick, 2004; McCutcheon, 1990; Saldaña, 2013). Once again, I recorded my thinking about the group as a whole in a short reflective note in my researcher journal so that I would be able to revisit my thoughts at a later time. I initially anticipated that at this stage I would also have new codes to add to my researcher codebook but what I actually found was the opposite—with each new connection I made, the threads connecting my 13 tentative categories started to tighten and take shape.

Cross-Group, Cross-Participant Interview Interpretation and Analysis

My cross-group, cross-participant interpretation and analysis process focused on considering all interviews together as a collective whole. At this point I spent time making connections between and among participants, linking potential themes, and sorting and assembling thematic categories in order to refine the 13 tentative categories that had been established during the within-interview interpretation/analyses (Seidman, 2013). Thematic handcoding on individual transcripts became less of a focus at this point as I turned my attention to marking sections of transcript text that seemed to have similar and differing perspectives on a topic—I used margin notes to indicate connections. I also returned to the visual tool I created during the within-interview interpretation/analyses in an attempt to organize my participant data into more fixed themes and subthemes. I found this iterative process to be complex and challenging as it seemed I was collecting, analyzing, organizing, and reorganizing all at once, across participant transcripts and my reflective notes about them (Creswell, 2008). I relied on the colour-coded highlights I made on transcripts to alert me to possible links that I might otherwise have missed had I reviewed for words and phrases only. At times I found it easier to scan the many transcript pages to look for highlighted colour combinations. I marked interesting connections by placing corresponding coloured adhesive notes on the page so I could quickly and easily locate the connections later. I paid attention to pauses, moments of silence, whispers, and laughter and looked across all transcripts to see if patterns emerged (Seidman, 2013). Determining my eventual themes and their order was challenging, as I found that almost every theme and subtheme connected in some small way to the others. I spent a significant amount of time considering how thematic threads could best be woven throughout my dissertation to tie it all together. I recorded my reflections in my researcher journal so I could revisit my thoughts.

Summary of Chapter Three

I began Chapter Three by situating myself in the study in order to communicate to the reader how my life experiences have shaped my perspective and influenced every aspect of my research study. I supported my methodological decision-making by clarifying my use of qualitative research, one-on-one interviews, and case study research in particular. I then reviewed all of the ethical considerations I attended to in the design and implementation of my study. From there I discussed my sample selection technique, participant selection criteria, and the processes I used to invite individuals to participate in an in-depth audio-recorded interview. I provided for the reader brief introductory participant profiles to further personalize my participants for the reader. I then highlighted my interview setting selection process. Data collection procedures followed, and I attended specifically to the use of one-on-one audio-recorded interviews, the General Schedules of Interview Questions, and my use of a researcher field journal. Next, I shared my transcription processes and explained how my study addressed

issues of internal and external validity. I included a discussion of the strategies I used for data interpretation and analysis before concluding with a summary of the chapter.

CHAPTER FOUR: DATA INTERPRETATION AND ANALYSIS

In this chapter I share the interpretation and analysis of my data from my research study around the school experiences of students with life-threatening food-induced allergies and anaphylaxis as perceived by children, parents, teachers, and an administrator. As I considered my data, I perceived the following five major themes centred around: (a) allergy identity, (b) safe-care strategies, (c) labels and labelling, (d) allergy communications, and (e) ethical disconnects. Each of the themes I generated from the study data also gave rise to a symbol, that is, a visual representation that seemed to exemplify each theme. I explore these images at the end of each thematic discussion. As well, three recurring subthemes emerged—time, trust, and transition and will be threaded through the discussion of my major themes. I include a recurring *personal aside* where I share my personal perspective. Throughout the chapter, I emphasize the emotions associated with food allergy experiences and I share this note as a signal to the reader so that s/he may reflect and perhaps empathize with the participants' personal stories as I did.

Researcher Interpretation

As data interpretation relies on my judgement as a researcher, I understand and acknowledge that my interpretation has been informed by my own life experiences parenting a child with severe food allergies and by my experiences as an educator. I know that when I saw emergent themes, marked passages, created tentative categories, and ultimately determined overarching themes and subthemes, these interpretations were informed by my own worldview (Merriam, 2009; Seidman, 2013). I am very aware that as a qualitative researcher I had to work carefully to avoid imposing my own researcher bias by allowing participants' voices and themes to emerge (Bogdan & Biklen, 2007; Seidman, 2013). Reflective notes made in my researcher journal were helpful to me, as the journal provided me a place to *write to think* and explore my own thoughts about the data that individual participants shared with me (Bolton, 2010). At times

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the reflective journal grounded me emotionally by providing me a place to confront my own ideas, beliefs, and feelings (Brookfield, 1995) so that I could write ethically and responsibly, without judgement of my study participants (Bogdan & Biklen, 2007; Bolton, 2010).

Data Interpretation

In each of the five major sections that follow, I offer to the reader my interpretation of my participants' data, organized into the following thematic categories: (a) allergy identity, (b) safecare strategies, (c) labels and labelling, (d) allergy communications, and (e) ethical disconnects. While my presentation of themes could have taken me in many directions, I feel the themes I ultimately chose exemplify my participants' lived experiences as individuals with food-induced allergies and anaphylaxis or as those who care for them both at home and school.

An Individual and a Shared Allergy Identity

Food allergy manifests differently for each individual (Cruz et al., 2007; Kumar et al., 2005; Larsen et al., 2016; Nettleton et al., 2009). Although many people have similar physical and emotional reactions when experiencing an allergic episode, the individual response is largely determined by a number of factors, some of which include: the offending allergen, coexisting atopic conditions, previous reactions, and the body systems affected (American Academy of Allergy, Asthma and Immunology, 2015; Bock et al., 2001; Burks et al., 2012; Kemp, 2003; Macdougall et al., 2002; Vilke, 2002). Each of the participants in my study who has, or cares for someone who has, food allergies, has crafted her/his own understanding of food allergy as a disease. For the child/teen participants in my study, their normal has grown from story, memory, and lived experiences. Parents have learned and adapted alongside their children, accepting their new realities and assuming new identities as allergy parents. Educator knowledge of allergy has

been shaped in part by awareness and experiences with individuals who have life-threatening food allergies.

It's Just "Normal"

Child/teen participants who have had food allergies since birth have never known a life without allergies. For them, food allergen avoidance is just a part of their normal everyday life. When asked about daily life with a food allergy, Robyn said, "it's pretty normal for me because my parents really care" and continued by explaining how her mom demonstrates care by baking "nonstop" for her so that she has something safe to eat (see forthcoming section called *Food Preparation: Care Procedures*). Although she could explain numerous strategies family members employ to keep her safe, Ashley initially said she "didn't know" how her food allergies affect our family—perhaps a reminder that she has not known a time 'before' allergies. Megan shared that her core group of friends, while initially "shocked" by all of the "stuff that [she] couldn't eat," view her allergies as "kind of normal." She continued, likening her friends' acceptance of her allergies to that of a vegetarian or vegan—just another kind of existence.

Stories that Diagnose and Confirm

I noticed when interviewing children who also had a parent participate in my study that the stories of early allergy experiences were not only a part of the parents' narratives, but the parent memories had been used to tell the child/teen participants information about themselves that they would not otherwise have known (Atkinson, 1995). For example, although Megan was aware that when she was an infant she was often sick and would end up in the hospital, she did not know the specific details of those early incidents that eventually led to her food allergy diagnosis—these details came from her mom. Diane recounted that when she was breast-feeding then 3-month-old Megan, she noticed that Megan would be covered in "head to toe eczema" and would pass "bloody stools." What followed for Diane was a pediatrician-suggested "restricted diet" that saw Diane eliminate dairy and peanut products. Diane added that while the passage of bloody stool did stop, the "eczema was severe" and by the time Megan was introduced to rice and wheat cereals at 5 or 6 months of age, her "colic" and "pain" would "flare up" again. By 18 months of age, Megan was labelled "failure to thrive," and though the pediatric allergist warned "she was very young to have this kind of testing done" Megan was tested and confirmed to be allergic (at the time) to dairy, wheat, egg, nuts, seeds, and codeine.

Like Megan, Robyn could not remember when she learned she had food allergies, just that it was a "long time ago." Barb, however, was able to fill in the details of Robyn's diagnosis story which is similar to both Megan's (see preceding paragraph) and Ashley's (see *My Context* in Chapter One). Barb shared that as a baby Robyn experienced "eczema," "hives," "stomach upset," "colic," and "had blood in her stools." On the advice of her sister-in-law (who had previously taken her own child to a pediatric allergist), Barb eliminated milk products from her own diet and "suddenly at the end of the 3 weeks" it was like Robyn had been "reborn as a totally different baby." Although Barb's family doctor "kept telling" her that "proteins didn't make it through [her] milk," Barb used a "food diary" and her spouse's "food allergies and sensitivities as a guide" to monitor Robyn's reactions. Barb had "everything figured out before [Robyn] was on solids" and had allergy testing done.

In addition to the aforementioned narratives, stories confirming allergic reactions also seem to be used by child/teen participants of my study to support their allergy identities. Interestingly, the stories the child/teen participants told of early reactions that occurred when they were outside their home environments most often occurred at celebratory functions. Megan recalled one story, told to her by her mom, of a reaction she had at age "3 or 4" when she was

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given "ice cream cake" by an adult at a birthday party. Similarly Robyn knows of an incident that occurred at a Halloween party when she was young where someone put cow's milk in her cup and she drank it. Ashley was the only one to speak of a severe reaction (in this case to peanut butter) that occurred at home.

My personal aside: A parent's perspective. It is interesting to me that the parent participant versions of stories have the same core offending allergen and reaction details, but the less important contextual details such as age or type of social gathering differ slightly. Perhaps as stories are told and retold, the peripheral details not required to convey cautionary messages change, or are lost—the real meaning being retained and added to the construction of identity.

Defining Moments Remembered

Just as the diagnosis and confirmation stories addressed in the previous section contribute to the construction of an individual allergy identity, each child/teen participant in my study recounted one or more significant allergy-related memories that have been defining moments for them in terms of understanding or learning from their allergies. Likewise, parents noted events that signaled to them the extent of their child's health concerns or reminded them of the need for constant vigilance. Educators also experienced key moments that pushed the boundaries of their allergy awareness. I share participant memories and accompanying emotions to show how memories can shape allergy awareness and understanding of self and/or others.

Accidental exposure. Megan recounted that at age 8, while at her great grandmother's house, she experienced "really bad stomach pains," had "hives all over," and had "trouble breathing" after eating "linguine salad" that had "parmesan cheese" in the dressing. Although Megan did not articulate the emotions she felt during this reaction, it seemed evident to me during the interview that Megan's memory of the incident was something that has stuck with her,

perhaps as a cautionary tale. Recalling the same incident, Diane remarked that Megan has not had a "severe reaction in quite a while" and suggested it is because "she's been trained."

The body remembers. Ashley shared a memory of a time when on an out-of-town family trip "a really long time ago" we walked into a restaurant and she had an immediate physical reaction. She said:

I walked in and honest to god, I got hives as soon as I walked in the door and I just kept saying "I can't breathe, I need to go." And so my dad was racing me around the town, we didn't even know...trying to find a grocery store so I could get Benadryl®, cause I guess at that time, we didn't carry it on me. And I just remember...to this day, I have never had a reaction where my throat felt tight for the next week. And I remember driving home and all I could talk about and think about was "why is my throat so tight? Am I going to die of this? Why is this happening?"

After sharing this memory, Ashley recalled a reaction that occurred sometime shortly after the restaurant incident. She "just knew" from the previous restaurant experience that "it wasn't a normal reaction" and something was seriously wrong.

My personal aside: A mother's perspective. I wonder if for Ashley, self-awareness and trust of her physical responses have been ways of knowing. As a mother, I have witnessed my daughter's immediate physical reactions to her offending allergens—her body instinctively recognizing and responding to what is happening seemingly before allowing her to think through and process the physical reaction she is experiencing.

Reliving the oral food challenge. When Megan was seven she underwent an oral food challenge to determine if she had outgrown her wheat allergy. She recalled being uncomfortable and really "scared" to try the food:

It was just the room with all of the doctors and all of the equipment around me it was kind of terrifying and then eating something that I wasn't allowed to eat for like my

whole life, and knowing that I could be allergic to it—it was kind of scary. Diane shared her own memory of the same "extremely scary" oral food challenge test. She remembers the pediatrician, "her residents," and a "team of doctors in the room" with a "crash cart, EpiPens®, [and] epinephrine laid out." Although the wheat challenge occurred 8 years prior to our interview (and had a positive outcome for Megan), it was as if during the interview, time slowed and I had a close up view of the scene in the hospital. Diane's emotional tension was palpable—a mix of fear and strength. She shared:

She's 7 so she knows what's going on and for 7 years we're telling her don't put anything in your mouth. . . . And now I had to bring Cream of Wheat, and we put it in her mouth because she wouldn't take it herself, I had to put it in her mouth and be strong and then tell her to swallow. And she was sitting there . . . shaking her head, like "nope, nope" because I mean, she knows that she'll get sick.

After the 6th of ten hours in the hospital without any reaction to wheat, Grant went "downstairs" and came back with a "big bag of licorice" for Megan to try "because she could never have licorice because there's wheat in it." The negative memories and positive outcomes the family shared around Megan's wheat challenge have not only expanded her dietary options but have also become part of Megan's allergy identity.

My personal aside: An empathetic parent researcher's perspective. As a mother of a child with food allergies, I empathized when Diane and Grant recounted their daughter Megan's oral food challenge test. As researcher, I felt emotionally caught in the trauma and hope tug-of-war that must have been Diane and Grant's decision to allow Megan to try wheat. I also seemed

to experience in the interviews the relief that both parents felt—though as a parent I remained fully aware of how a different test outcome could have affected Megan and the family.

"New and improved taste." Barb shared her memory of a time when her family was "late" in picking up a friend. Robyn was 9, and she grabbed a store brand "crispy rice marshmallow square" treat to eat in the car. Barb noticed that neither she nor Robyn had brought an EpiPen®, but because they were "in a rush" said to Robyn, "it's fine, you're only going to eat things we trust, let's go." When Barb heard Robyn call "mom" from the back seat she "knew right away [that] something was not good." They "turned the car around and raced back to the house" to get her medication. Barb stated that Robyn was eventually "okay" but her "mouth was really tingly and her throat was closing up and she was very, very anxious—which doesn't typically happen." Barb admitted that at first she hadn't noticed the "generic looking sign" on the treat box that read "new and improved taste" and "couldn't figure" out what had caused Robyn's reaction to a trusted food item. "Eventually," when Barb pulled out the treat box, she noticed and realized that they had put in frozen egg yolk—not just a little bit, it was the second ingredient and I just . . . I started crying immediately. That was her [Robyn's] first exposure to egg, and when she had her first RAST test done, the Sick Kids' nurse

couldn't even believe it. Her RAST on egg was 47 [see definition in Appendix G]....

So, there was every probability that that first egg exposure could have been anaphylactic. The emotional impact of Barb's memory and what it could have meant for Robyn was evident in the interview. One might speculate this incident now influences the family's strategies, decisions, and communications around label-reading, consumption, and/or travel.

"Just do it." As the only participant in my study to have administered epinephrine, Angela admitted that in that instant before injecting the student, she "hesitated" because she "wasn't sure if there were enough signs" and she "wasn't quite sure if it was time to do it." Angela recalled in detail the exact moment when she realized she would be giving the EpiPen® to the student who was having an anaphylactic reaction:

I kind of questioned whether or not I should do it and the girl actually told me "just do it." So she was laying right there on the floor in front of the staff room so I got it out and my hands were shaking, I was very nervous but I sort of went through all the training that you know, I talked myself through it. And I was actually looking at the container and trying to read it and my hands were shaking—I was really nervous. But I was trying to read the steps again just to remind myself. I just popped the cap off and I held through her jeans into her thigh and I remember they say to count to 10 and then somebody said count to 10 again because you're so nervous that you're counting faster than you should.

Angela's understanding of allergy and anaphylaxis changed the day she injected a student with an EpiPen®. Angela said it "was very scary" experience and since she has "oftentimes quoted that instance back when parents have questioned why we [educators] are so strict about things." Angela explained further, saying that using an EpiPen® is not "like putting cream on something...it's not a cure, it's not an everyday remedy."

Relationships Contribute to a Shared Allergy Identity

It seems apparent that the constructed allergy identities of the children and parents in my study were in part influenced by their relationships with others. The three girls and Grant (the only father in my study) acknowledged that Moms in particular, provide physical, social, and emotional support/security for their children with food allergies (see also *Unexpected Circumstances*). Relationships with family members and friends are affected positively and negatively by, and as a result of, allergy.

Mom's the word. There seems to exist a special relationship between mothers and their children with food allergies—perhaps born from giving life and/or from the desire to preserve it. Kim's use of the word "we" when speaking of her son's allergies gave me the impression she had assumed his allergy identity as part of her own. For example, during the interview I noted phrases such as "when we did the skin test we went . . .," "we haven't had puffers," and "we don't do [ice cream] floats anymore," though at first I was unsure as to why I felt drawn to the "we" phrases (Saldaña, 2013). On the surface, the phrases could suggest that Kim accompanied her son to the appointment, no one in Kim's home has asthma puffers, and all family members are eliminating ice cream floats from their diets. It was only when Kim whispered that her husband had consumed a meal on an overseas flight (while she and her children refrained) did I infer a possible new meaning—solidarity as a physical and emotional support strategy. "When we did the skin test" became part of a shared allergy story, memory, and experience, while "we haven't had puffers" and "we don't do floats anymore" became the reminders and rules of a life with boundaries dictated by allergy.

In Grant's interview he shared that "as a mom" his wife Diane handles "most" of the medical appointments for their children. He admitted that he does "go to the appointments" and he has "made appointments" but Diane "carries more of the burden . . . especially when it comes to specialist stuff regarding [Megan's] allergies." This idea of the mother as knowledgeable was also reiterated when he said that he was not aware of an instance where Megan has been made fun of or teased because of her allergies. He explained that he "[hadn't] heard of it" and Diane has not "told" him of any situation, clarifying that "she would know—moms know everything." The same idea was shared by Robyn in her interview. She said that one time when she was having a reaction, her dad "called mom cause he wasn't the allergy expert" which I, as

researcher, found to be an interesting statement because Robyn's dad does have food allergies and Barb does not. One of Robyn's "rules" is that she can't eat anything that is not from home "unless mom approved it," which again indicates that Barb is the trusted authority on Robyn's allergies. Angela also spoke of the "safe mom-approved treat" that is sometimes sent to school by parents of children with allergies so that the kids can have something special if an unexpected snack, like birthday cupcakes, is sent to school by another parent. Both Kim and Barb spoke of ensuring that they had purchased and sent a special safe treat for their own children to enjoy at school in the event of an impromptu celebration—most often during the elementary years.

Supportive and not so supportive family members. Grant shared that he and Diane have a "healthy relationship" with Megan. He remarked they have had to "spend a little more time with her because of the food allergy" and suggested it "kind of brings you a little closer because you are micromanaging her life a little better than, say, if she didn't have allergies." In a similar way, Barb talked about Robyn being a "sensitive little soul" and admitted being "pretty protective" of her, stating, "even if she didn't have allergies [she] would probably be more protective of her just for that reason."

Younger siblings also seem to take on care roles. Barb recalled a time when, at their grandparents' home, Robyn's sibling noticed and stopped Robyn from drinking soy milk that she is allergic to. Barb explained that "the packaging on the Natur-a rice milk is very similar to the packaging on the Natur-a soy milk and [Barb's] mom bought the wrong one." Diane also discussed the protective roles that Megan's siblings have taken on announcing they've "washed up" after a meal or taking over cleaning duties. Diane noted that one of Megan's siblings already knows all the "by-products of casein or whey" and helps with label reading.

Diane shared that she has a "very tight, close-knit family" and feels everyone is very supportive of Megan. Kim could not recall "any issues" with close extended family members, although she once had to explain to her grandmother why her son couldn't eat chocolate-covered raisins because they were "kind of worried that it's easy to mix them up" with the chocolate covered peanuts. Family members who are not that close to the child with the allergies, or family members who have their own "perceptions" about the limits of the child's allergy, do challenge relationships. Kim talked about being hurt when her husband's brother and his family were staying at her home. Kim's in-laws invited her brother-in-law's immediate family out for dinner but neglected to invite Kim, her husband, or her children despite the fact they were all staying together at her home. She said, "you know when you don't want to go but you're insulted that you didn't get invited" and thought the exclusion was due to her son's allergies.

Supportive friends. Friendships play a role in the creation of an individual and a shared allergy identity, yet not all relationships are easily maintained. Grant shared that their family used to "hang out" with another family, but he and Diane determined they "can't go there" anymore. He explained their friends' home environment was not safe for Megan because of the "dogs and cats running around and peanut butter all over the place." Grant said "eventually you spend less and less time with those friends," noting it is not out of any "evil" intent.

For the children in my study with allergies, they all spoke of having a "close" or "core" group of friends who understood and respected their allergies. For Robyn, who had a negative experience with a student who was "dangling allergens" (see forthcoming *Target* in my fourth theme *Communicating Allergy*), her friends helped her to advocate for her safety. Robyn remembers saying "get that away from me" but not being taken seriously by the boy. She realized when her friends "stood up for her" and "even the people who [she] didn't think would,

came in and were like 'dude that's actually not cool, you can't do that,'" that she was being taken seriously. Robyn's family also felt the support of friends when, at an out-of-town sporting event, the group of 20 went to a restaurant. Since Barb knew that Robyn "wouldn't be able to eat the food at the restaurant" they brought Robyn's dinner with them. When restaurant staff refused to heat up Robyn's dinner, the whole group "got up and walked out" in support. During the interview, it seemed that Barb really appreciated this act of solidarity in support of Robyn. The group act not only communicated a message to the business owner about customer needs but perhaps more importantly, it was a demonstration of "fairness, justice, and caring" in action that could serve as a model for the ethical treatment of individuals (Stefkovich, 2006, p. 17; Stefkovich & Begley, 2007). One might expect that friendships were solidified in this instance and, as well, expectations of equity established.

Positive Perspectives

Negotiating daily life with a food allergy can be challenging; however the individuals in my study also illuminated positive aspects which have contributed to an allergy identity. Here I share food allergy and anaphylaxis experiences that have provided individual participants with unique perspectives about themselves and others.

Gratitude. In her interview, Barb admitted she "used to feel jealous of a lot of other families that didn't have to deal with allergies." Her view has changed, and she now feels Robyn's allergies help the family "maintain" a sense of gratitude for what they have. She explained, when they travel out of town for appointments they "see kids who are really sick and [they] know that as long as [they] feed Robyn properly, she's going to be healthy." Barb accepts that "everybody's got challenges in life" and they teach you to "be thankful for what you have." **Opportunity.** Kim talked about her family having had the opportunity to attend a professional baseball game where a designated peanut/nut-reduced zone was created by request of an allergy support organization. She acknowledged in her interview that her family "probably wouldn't have done this" had it not been for the allergy advocacy group. Kim was pleased that her son had the "best birthday present ever" that year and was grateful for the support network.

"It could be worse." When reflecting on her family's challenges with food allergies, Kim thought "it could be worse" and that her son "could be allergic to all these different things." For Kim, she felt that "in your own little world, you can live without peanuts." Reflection on and about lived experiences with food allergy allows individuals to see beyond their own realms.

Empathy. Angela feels that children with food allergies "of all people, can relate to people who have to deal with a struggle—whether it's an allergy or an injury or maybe being different." Diane echoed a similar feeling about her own daughter, suggesting she is "very thoughtful of others because of that, because she knows what her struggles were . . . and not just other kids with food allergies, I think just other kids with any kind of challenges."

The EpiPen®

As it happens, all three child/teen participants in my study have referred to the EpiPen® as their prescribed brand of epinephrine auto-injector, and so I use that term here. For the minor participants in my study who have life-threatening food-induced allergies and anaphylaxis, the EpiPen® has become part of their lived realities and individual identities—it is as much a part of who they are as the allergy is. The EpiPen® provides a sense of security for the girls and their families, and they rarely go anywhere without "two" EpiPens® as was shared in interviews.

Summary of an Individual and a Shared Allergy Identity

This first identity theme acts as a foundation on which forthcoming themes and subthemes will be constructed. In the exploration of allergy as an individual and shared identity, I felt it important to honour participant voices and lived realities by ensuring the reader is aware that although food allergies can have common expressions, allergy manifests differently for each affected individual. As well, it seemed important to draw attention to and represent the experiences of the child/teen participants in my study as they view them—just their "normal" lives. Participant stories, memories, and perspectives all play key roles in the construction of allergy identities. Stories illuminating the identity theme centred around diagnosis and confirmation. Memories, incidental and corporeal, resonate and remind, while perspectives change and grow as individuals become more familiar with allergy and more attuned to their body's responses. Allergy identity also seems to be constructed from shared experiences. Relationships with mothers, family members, and friends were explored. The EpiPen® as both a part and symbol of allergy identity concluded the discussion.

"We are shaped by our diagnoses, but we are not reduced to them" (Rosenberg, 2009, p. 803).

Responsibility: Rules, Routines, and Safe-Care Strategies

Ensuring the physical safety of children with food allergies can be challenging for families and school communities, especially when multiple offending allergens are involved. Such situations are further complicated by the nuances and variations of the manifestations of allergic disease in the individual and the unpredictability of their allergic responses. Participants in my study shared with me the rules, routines, and strategies they employ to protect those living with life-threatening food allergies and anaphylaxis. I begin this section of the chapter by sharing how families create and maintain healthy home environments for their loved ones. I then discuss the application of trusted safe-care strategies outside of the home. As children and teens with food allergies mature and can more independently address their own allergy-related needs, responsibilities previously assumed by parents and/or caring adults begin to shift to the children with allergies. I close this section with a look at how for the participants in my study, the *purse* symbolizes the transfer and acceptance of responsibility from parent to child.

"We Make Rules"

Within the rigid life-or-death boundaries that food allergies present, the children and parent participants in my study highlighted and reinforced the necessity for strict observance of the *rules* that address individual needs and contexts. I call attention to rules at the outset of this thematic discussion of responsibility as a signpost for the reader to take note of the times when rules become routine, when routines revert back to rules, and when rules or routines are applied to new contexts requiring trusted safe-care strategies.

Explicitly or implicitly stated rules seem to provide the families in my study with operational structures by which individual realities are normalized, environments are controlled, and behaviours regulated. Rules established to create safe home environments become common routines and there is an expectation of respect and responsibility for adhering to the established family norms (see forthcoming *Home Safe Home*). For example, participants have accepted household operations rules that do not seem to require explanation or family discussion such as "no nuts" in the home or the understanding that the telephone "landline" will be retained for security purposes even though "a lot of people [are go]ing to cell phones." Explicitly stated household rules, however, seem to require increased monitoring. For example, in Barb's home, family members are required to label foods that are off limits for Robyn and "serious trouble" results when the rules are broken.

Most of the rules that participants shared emerged when discussing a context change that saw child/teen participants venture away from their safe home environments—the routines becoming articulated rules again and new situations resulting in the creation of new rules or guiding principles. Interestingly, it was the new experience procedures that the child/teen participants seemed to actually call rules; everything else was just normal life practices. For example, all three girls talked about ensuring they not only had their EpiPens® on them but also a charged cell phone when going out with friends (see forthcoming theme *Communicating Allergy*). As well, I noticed that many of the rules the girls shared were expressed using firm negative vocabulary words and phrases followed by a description of the restricted behaviour such as: "I can't have," "I can't go," "I can't eat," "I can't buy," "I can't participate," "I can't eat in the cafe," "I can't eat out," "I can't really do that anymore," I can't do certain things or go to certain places," "I never," "I don't," and "we aren't allowed." Sometimes the rule was followed by a qualifying statement. For example, Robyn's "I never eat dinner at a friend's house ... I have, but ... I do take my lunch and we have to warm it up" suggests that the way that she can participate in new experiences might feel less than ideal to her. Similarly, "I can't eat anything if it didn't come from my lunch, unless mom approved it" also has a qualifier on it suggesting there are times when participation can occur but within controlled circumstances.

Home Safe Home

Parents in my study spoke at length about shopping, food storage and preparation procedures, and strategies they employ in order to safeguard against cross-contamination or accidental contact with their child's offending allergens. Very few of the reactions that the children/teens in my study talked about occurred at home—likely because families have worked hard to ensure safe home environments. For Ashley, home is her "safe space because nobody eats it [nut products] here," and although she is the only participant to articulate this sentiment, one might expect that the other two children in my study, if asked directly, might have responded that their homes are their safe spaces as well.

Elimination and avoidance. The number one strategy to ensure the safety of individuals with food allergies and anaphylaxis is strict allergen avoidance and quick access to prescription epinephrine (Burks et al., 2012; Garcia-Careaga & Kerner, 2005; Pitchforth et al., 2011; Rouf, et al., 2011). For the participants in my study, *avoidance* takes on multiple meanings depending on the severity of each individual allergy someone has; the fewer the allergies, the easier it is for families to accommodate. For example, since Kim learned of her son's peanut allergy approximately 18 years ago, the family has "avoided everything nuts, [or] may contain traces of nuts, and so far so good." In the last 4 years, Kim has had to add coconut and sunflower seeds to the list of items her son avoids. Ashley, Tina, Kim, and Grant reported that there are no nut products or products that may contain nuts in their homes. Grant explained there are "obviously no nuts in the house whatsoever. There's not a nut product I can find, and I don't miss it." He did indicate that Diane does keep "real peanut butter at her work" and Megan mentioned this as well. When asked if it worried Megan that her mom enjoyed peanut butter at work she said, "no, because I know she's careful. She's extra-protective." Barb noted that because Robyn's "nut allergies are not as severe as milk and egg and soy and pea," the family does keep nut products in the house although they "don't eat them much...they're contained in other things." Although Robyn's egg and milk allergies are her most severe, her family does have those foods in their home. Barb remarked, "I know a lot of families wouldn't do that ... just clear out the allergens, but considering how many things she's allergic to, it doesn't seem fair to force [her brother] not to be able to have things like that in his diet." Megan's family also has eggs and dairy products

in their home but take extra precautions when preparing meals that contain these ingredients (see *Food Preparation: Care Procedures* below). None of the participants in my study spoke of eliminating fruit or vegetable products from their homes, just the diets of the individuals with the food allergies. For example, although Ashley cannot eat apples or strawberries, we can have them in the home as her reactions to these food items occur only when she ingests them, which is very different from her nut allergies which are more severe.

Substitution. Parents reported making it a priority to prepare meals that all family members can eat with minor modifications made for the child with the food allergy. For the participants in my study, *substitution* occurs in the form of whole meal replacement, ingredient substitutions or replacements, and/or variations of family meals. Grant said that "a while ago [they] were always serving two different meals," but they try to avoid that as much as possible. He noted that "ingredient listings in the grocery store are way better now" and help the family prepare "Megan-friendly" meals. Barb commented that they "almost never have completely separate meals" because she doesn't "have time to make two separate meals." Neither Kim nor Ashley spoke about having two separate meals made as a result of a food allergy in the home, which may be due in part to the fact that nut products (the primary allergens avoided in their respective homes), are perhaps not as pervasive as the food allergens Megan and Robyn avoid.

In order to accommodate Megan's milk allergy, the whole family uses "vegan butter instead of actual butter" so "that way there's no giving her the wrong butter." Megan drinks soy milk instead of "real milk," as do her siblings based on preference. Although Diane and Grant prefer cow's milk, they did not have it in their home until "3 years ago" when they felt Megan was old enough to "read and could understand." Diane worried Megan might accidentally grab the milk instead of the soy milk so they instituted an organization system where milk-containing products are located at the back of the refrigerator and all of Megan's safe products are at the front—"so she should not be digging at the back of the fridge." Unlike Megan, Robyn drinks rice milk because she cannot have soy, almond, or goat milk.

At times, both Megan's and Robyn's respective families use a powdered egg replacer in recipes that would normally call for eggs to be used. Barb reflected on "the amount of time [she] spend[s] baking—wow! It's a lot of baking because [Robyn] can't have any kind of bread that isn't homemade." During her interview, Robyn seemed pleased, proud almost, that when she "went off gluten, [her] mom started baking nonstop for [her]" making things like "bread," "muffin," "pancakes," "hamburger buns," "cakes," and "cupcakes." Robyn recounted a time when she had friends over for a party and "everybody had mom's cake and they said that mom's cake was better than real cake." Robyn admitted to being "really happy to realize that [her] food is just as good as theirs." It seemed that Barb's baking allows Robyn to feel a sense of social inclusion with family and friends. Although Kim did not discuss specific ingredients she substitutes, she did note that "all of their stuff is home baked" and she makes many food items "from scratch" to ensure her son's safety which she surmised is much "healthier" for the family.

Exclusion and temptation. Megan and Robyn both spoke of times when they found mealtimes hard. Megan remarked that when the family is "in a rush" other members might have "sushi or pizza and then [she] would have to make something else." Robyn felt "tempted" when her family goes to Tim Hortons "because it smells so good" whereas places like Dairy Queen don't tempt her as much because "Dairy Queen doesn't smell like anything." Robyn also talked about "covering [her] eyes" when her family goes to bakeries because the pastries "look so good." Kim noted that "it's just hard—the social thing" in our "foodie type of world." She explained that she's "not worried [her son] is going to go out and go to Dairy Queen" or that

"he's going to go into Tim Hortons and eat something" but, as a researcher, I inferred that it perhaps troubled Kim that her son could not fully partake in social activities that his peers did.

Holidays are hard. For children with food allergies and their families, holiday time can be emotionally challenging—with treat inclusion often being more concerning than meal preparation. Diane claims to "hate Easter, cause everything's chocolate" and "hate[s] Halloween because it's really sad when [Megan] goes through her bag . . . and she ends up this little baggie of what she can have." Putting strategies in place at home helps with social inclusion, though the strategies do not always transfer easily away from home. Ashley discussed giving her Grandpa Halloween candy that has nuts in it and, similarly, Robyn talked about her Halloween candy trading strategy. She explained: "I trade with my mom. All my chocolates I give her and she'll give me a bag of chips back. Or I'll give her a giant one and she'll give me two bags." Grant discussed meal preparation procedures at family gatherings and talked about how everyone is "very supportive" of Megan. He said that they "really cater to her and they don't mind," sharing specific examples such as not choosing a "Butterball®" turkey at Thanksgiving, "not putting the stuffing in it," or saying that family members "always call" to confirm recipes.

Buying and trying new food items. When it comes to grocery shopping, Ashley reported that it is more likely her dad who will come home with new products for the family to try while I am more of a "stick to the brands you know" kind of shopper. This was similar to Diane's description of Grant as the parent who is more inclined to bring home a new food item for Megan. Diane admitted she "would never actually pick that [new] item up" because it's not on her "master list" of products that she purchases regularly. Diane also explained that if Grant does come home with a new product, he has both her and Megan read the label to be sure that it

doesn't contain any of Megan's offending allergens. Barb stated her spouse "hates grocery shopping" so she takes on that task, though did not elaborate on food purchasing routines.

Just because a new food item comes into the home does not mean it is consumed immediately. There is a process that the families follow and the 'home' conditions need to be optimal before parents consider having their children with food allergies try food items. Diane shared that she reads the product label and has Megan do a "taste test" by touching the food first with her finger to see if she reacts, before Megan "takes a little lick" and they wait "15, 20 minutes." If Megan is fine, they will progress to touching the food on Megan's lips or her tongue after which they will wait 30 minutes, watching for a sign of a physical response. Diane explained that they will allow Megan to try new foods only when both she and Grant are home just in case Megan does have a reaction; Diane wants Grant there for "support."

For Robyn, trying new things is not often possible. Just this year, she and her mom have discovered that instead of a taste test, Robyn can do a smell test of any food that is "not cold." Robyn says it's "not weird smelling" but she "just smell[s] it so [she has] an idea of what it really tastes like" and she "like[s] that." It's not only new foods that parents and children are curious about. Like Robyn, there are foods that Megan cannot try. Grant did speak about wanting to "dab" Megan's forearm with the slightest amount of raw egg to "see how severe the hives would get" so they could know if her allergy was changing. The last time Grant mentioned it, Diane vetoed the suggestion saying "no, let's not do that today, it's a long weekend" perhaps implying they had family commitments and a reaction would interfere with plans or meaning hospitals might be busier than normal and they could spend too much time awaiting care.

Food Preparation: Care Procedures

Parents and children discussed food preparation procedures, routines, and rules they have instituted to keep Robyn and Megan from coming in contact with their offending allergens. Also included in this section is a discussion of kitchen tools and at-home cleaning protocols.

First up. Grant talked about cooking for Megan and serving her before other family members when he knows that he will be cooking something that contains Megan's allergens. He shared that the morning of our interview he made Megan a bacon sandwich on "Megan-friendly bread" with bacon, margarine, and ketchup before preparing his own bacon sandwich with mayonnaise, and scrambled eggs for the other children (two food items Megan cannot have). Grant talked about how wanting mayonnaise instead of ketchup, or eggs with bacon, requires clean tools and full attention:

You've got to grab another clean knife out of the drawer and you cannot stick that mayonnaise knife back in the margarine container, or near the bacon. And same goes with the eggs, cause you're not going to take a spatula that you served the scrambled eggs with and scoop it into the bacon dish . . . you just can't.

The family has applied the same "make Megan's first" strategy when preparing meals with their extended family members. Diane gave the example of family barbecues where the grill was first cleaned so that Megan's homemade hamburger could be cooked by itself before any hotdogs, sausages, or other burgers with cheese were put on the grill. Diane was sure to note that she is "also there supervising" the meal preparation process as an extra measure of care.

Set aside: Addition and/or isolation. Barb stated that when she and her spouse are preparing a family meal, they will often "make something and put [Robyn's] part aside or [they] might put something on top of that" for other family members. Barb used tacos as an example

and explained that Robyn would be served her taco and then the other family members who wished would add an allergen-containing product like cheese to their meals.

The concept of setting something aside was also mentioned by Diane as a strategy that her extended family members use at gatherings to isolate Megan's food in order to add her safe food products to it. Diane used the example of a Christmas dinner gathering where, when the vegetables are cooked, a portion is transferred to a small bowl for Diane to add Megan's vegan butter to it. Further, they communicate to all family guests that "this is Megan's section, do not touch" so that everyone is aware. Diane emphasized the importance of everyone eating together and noted that although sometimes Megan's food is prepared ahead or needs to be reheated, they make a point of eating "together." Diane talked about being "in the kitchen just helping out" but acknowledged that everyone "knows it's a control thing" which offers the family peace of mind.

Accidents happen. Grant admitted that "all of us have screwed up" and having to tell Megan that he "dropped a pile of egg on" something and that now she "can't have it" is hard. When accidental cross-contamination does occur, like using the butter knife in the margarine container, extra care is required to address the problem. He said that while his family tries not to throw food out unless they "absolutely have to" they will often give the product to an extended family member or take a "red marker" and write "no Megan" on the package. Barb also spoke about having strict rules around margarine and jam in order to avoid cross-contamination. She said when her kids go to visit her parents during holidays, her parents will start fresh and "throw out whatever jam and margarine they have in the house" before the kids arrive, just to be sure.

Separate tools. Diane recounted that when Megan was younger the family had two toasters and they would never put Megan's rice bread into their toaster. With decreasing RAST test scores, Diane "integrated" Megan's bread into the family toaster. Megan also spoke of the

toaster in her interview, reporting that currently, one side of the toaster is designated for her and the other side is for her family members.

In Barb's home, they have "special spatulas" for eggs though they do not have separate frying pans for eggs and other food items. Barb also said that she "always put[s] down a cutting board or a plate" when making Robyn a sandwich to ensure that "her food does not come into direct contact with counters." Similarly, Megan shared that when she prepares food, she uses her own cutting board that never comes into contact with her allergens. Grant also mentioned using a separate pan and cutting board when preparing and serving something like pizza for Megan. Again he stressed it is important to "prep hers first" before taking out the "regular cheese [and] pepperoni pizza" for the other kids so that way you don't "mix up [Megan's] meal."

Cleaning protocols. Barb was adamant that Robyn is not to wash the dishes of family members who have eaten an allergen-containing food item. The same rule applies for Megan, as she does not clean up after anyone who has consumed a food she is allergic to—she said "they always have to clean up after when they cut cheese or things [she's] allergic to." Grant was the only parent to come right out and directly state that food preparation "takes longer" and "there's more dishes." He also admitted to being "a little bit of a clean freak" who likes to "clean up as [he] go[es] along." Diane also addressed the topic of cleaning up after meals:

So, we just cooked scrambled eggs, once that's all done and we eat (so we eat at the island), then everything comes off the island, then I take Lysol Kitchen. . . . I disinfect my stove and I disinfect the counter that I work at. . . . So my house always smells like disinfectant all the time.

Diane talked about the importance of vigilance, stating "you have to be watching all the time," especially with her youngest child who sometimes forgets to wash after dinner and then goes and plays on the family computer, which she noted, then becomes something else to be cleaned.

Barb uses a "wash and inspect" strategy in her home to ensure that anything that has come into contact with egg is washed by hand. Diane also hand-washes things like frying pans that have been used for eggs but afterwards, "it still goes in the dishwasher" just to make sure. Although she does not use the strategy in her own home (because they do not have nut products in their home), Kim remarked that prior to their arrival, a relative whom they visit often, uses a "triple wash process" for anything that might have come in contact with nut products, which seems to give family members an added sense of security.

Diane was the only participant to speak of the relationship between food allergies and laundry. She used the example of her husband Grant who tends to announce to the family when he is cooking, which "drying towel" is off limits by saying something like "this is my egg one," which signals to family members which towel will go "down in the laundry" when cooking is complete. Although she said that "normally any wash would be fine," Diane did report that her family has mostly white kitchen linens so that she can "Javex® everything" that might have come in contact with Megan's allergens so Diane is confident it's "good to go" and safe.

The Application of Trusted Safe-Care Strategies Outside of the Home

Venturing beyond the confines of the safe home environment presents unique challenges for individuals with life-threatening food-induced allergies and anaphylaxis. The children and parents in my study stressed the importance of awareness, planning, and preparation for participation in activities outside of the home. It may not be surprising that the most obvious safe-care strategy that the child/teen participants discussed was "bring[ing] an EpiPen®
everywhere" they go. In the following subsections, I detail some situations that have required rethinking of the daily life rules, routines, and responsibilities that are informed by allergy.

Birthday parties. All of the children and parents talked about birthday parties as one of the first social experiences outside of the home. Diane shared that when Megan was 2 years old she was at a children's birthday celebration and was given a bite of ice-cream cake by the grandfather of the child, which resulted in Megan being hospitalized (see *Stories That Diagnose and Confirm*). Even though Megan had parental accompaniment at the event, Diane and Grant learned from that situation that they required different strategies to ensure Megan's safety. As soon as Megan could speak, Diane and Grant trained her to say "do not feed me" and when they took her to birthday parties she would have a "name tag" that would say "please do not feed me."

Diane shared that "when she was invited" they would "bring [their] own food" to many birthday parties. When the "moms knew [her] personally," they would call Diane to discuss Megan's participation at the party. Ultimately, Diane would "pack something equivalent to what they were having" so that Megan could be included. She recalls:

So I would make a cupcake, out of what she can have, so when they have cake, she can have her cupcake. If they were having hot dogs, I would make sure I send her wiener, her bun, you know, and have all that.

Diane noted that in a small town "everybody talks, so you know" when it's someone's birthday. She recalls that Megan "missed a lot of birthday parties" and thinks it was because "parents were scared," "didn't know what to expect," or thought they didn't "have food for her." Diane "think[s] it was just the ignorance of parents, not realizing that [she] would have taken care of everything." Admittedly, Diane was "really sad and hurt and angry" on Megan's behalf but said that Megan's a "very private person" and has "never" spoken about not getting invited.

In Barb's experience, sometimes it was the other parents who created the conditions for Robyn's inclusion at a birthday party. She recalls in the "early years . . . parents didn't want [her] to leave" because "they weren't comfortable." She stated that the parents "sort of said 'you know she can come to the party but only if you stay because I am looking after all these other kids and I don't know what to do if your kid has a reaction." Barb admits that she "was that mom who was still staying for the birthday party when all the other moms were gone." Similarly, Diane also "stayed a lot at these birthday parties, until . . . [Megan] didn't want [her] to." She remembers being the "only parent" who stayed. Diane said:

I think the parents liked that because you know, I'd just help out, right. I would kind of be there as, not in her face, but talking to the adults, or serving cake or whatever. I just was kind of there as a helper, and I don't know if she [Megan] really realized that but it was just more to watch and make sure.

Parental accompaniment seems to be an effective strategy that allows a child with food allergies to participate in a social event like a birthday party while providing a sense of security for the adults involved. Security for the children is much more likely to involve bringing their "own food" and items, especially a "cupcake" which seems symbolic of birthday party inclusion.

Kim recalled a time when her son was younger that one mom went out of her way to ensure that he was included in the festivities. The party was held at a restaurant and, when Kim arrived, it was evident that the other mom had previously had a conversation with the owner as the "lady had actually cleaned out the deep fryer." Kim "certainly" felt good about that event and was pleased that her son could participate. In this particular situation, preparation strategies worked in Kim's favour; however there are times when parents of children with food allergies aren't so fortunate. Barb explained that "as long as she's got her own thing" Robyn is "usually okay" but stated that "one time [they] had to leave a party" because "it didn't even occur to [her] that [the host] would be serving cupcakes to all these 40-year-old parents . . . and [Barb] didn't have anything for Robyn." She admitted, "That's the only time it's ever happened in 12 years, but [Robyn] was pretty upset by that one."

My personal aside: A protective mother's perspective. Like some parent participants, I am also a mother who has had conversations with host parents about party food plans. I have also prepared food items for Ashley to bring with her to social activities like birthday parties so that she could participate with her peers. Admittedly, I have also stayed at social events longer than other parents—risking my daughter's social acceptance, just to make sure

Dinner and a sleepover? Robyn expressed frustration at the lack of social spontaneity in her life. She remarked that sometimes she just "want[s] to hang out with [her] friends" after school but if it was unplanned and she didn't pack "anything to eat for dinner," then "it has to be really short" or they have to make a "last-minute meal with stuff in the cupboard" that she can actually eat. Barb made an almost identical comment during her interview when she said:

We have to be a lot more careful with those than most families do. You know, having a friend call and say "hey, do you want to come to the hockey game with me on Saturday night?" and the plan is to like grab dinner wherever and go out to the game, you know she can't have that kind of spontaneous social life and neither can we. If we're out doing errands, we absolutely have to be back for dinner time, cause I'm only going to buy her fries so many times. So it's a bit of a lifestyle difference. The total lack of ability to buy prepackaged foods, or prepared foods, the restaurants, you know.

For Barb, planning for a social get-together requires two-way communication and responsibility. She feels that as Robyn's parent she needs to make sure that the friend's parents are "okay with that" and she remarked that "it's not just our comfort level, it's theirs too."

Ashley shared that sometimes she feels like she has to "make up really awkward excuses" to explain why she can't go out to dinner with her friends. She said that when she is completely honest, she just says "I can't eat out, I'm really sorry, I can't go." She mentioned that recently one close friend who learned that it is not easy for Ashley to go to a restaurant planned a dinner around her allergy needs. Ashley described what this meant for her:

It means that I can actually participate in what they're doing and be their friend and do fun things with them. When they don't, I mean it hurts but I mean they don't live it—they don't get it . . . I can't be mad at them for not understanding.

Like Ashley, Megan commented that she feels "kind of awkward" because she has to "bring [her] own food everywhere." She spoke of going to sleepover parties with friends and noted one strategy she uses is to "go after supper" because then she only has to bring "cereal and milk" for breakfast. In her interview Diane reiterated the same "after supper" strategy Megan shared but explained further that with cereal and soy milk, it is easier to avoid cross-contamination of allergens. She said: "I keep it very generic because I don't want . . . [her bread] going into their toaster." Diane talked about her treat communications with other parents regarding parties:

I'd always tell the parents that "okay, I'll buy all the chips and you know candy or whatever" for a movie night. So I will supply all that and make sure. Then I know, nothing comes out that she can't have, like a dill pickle chip, you know, or a salt and vinegar chip. She'll have her own kind of stuff. Negotiating the tension between physical allergy needs and social inclusion is a balancing act for the child/teen and parent participants in my study. If physical needs can easily be met by bringing food, inclusion is more likely to happen. If food allergy needs are challenging to meet within the social experience, it is more likely that the teens will avoid the discomfort by joining friends at a different time or by self-exclusion from the activity.

Eating at restaurants. The child/teen and parent participants in my study reported that they rarely go out to eat a restaurant and, in the odd instance they do, it is very hard. Robyn noted that "it's a treat" to go out because she "can't eat at very many restaurants." She did say that she "brings an EpiPen® everywhere—especially if [she] is going to a restaurant." Interestingly, all three girls indicated they can eat the "fries" at McDonald's, although this may change after the January 17, 2017 announcement that McDonald's® Canada will begin to offer menu items that will contain "non-packaged peanuts or tree nuts" and the "possibility exists for cross-contact between nuts and other menu items" (Food Allergy Canada, 2017). Robyn can also eat the fries at A&W, and Kim shared her son can also go to A&W although "a long time ago" he did have an allergic reaction after consuming a root beer float. Kim admitted "she didn't think about it" but later learned when looking at the company website that the "ice cream may contain traces." Ashley said that on trips she used to be able to go to Harvey's, but the addition of a fried dessert item containing hazelnuts now prohibits her from going there. She shared her disappointment saying that "it sucks because that was the one place we could actually go." Kim's family does not "eat out a lot," but she said that when they have "had to," for example for her mother-in-law's birthday, they have "called ahead" and have "never had an issue." Grant used similar language to Kim when he commented that his family doesn't "go out locally" and that the "only time [they] go out is when [they] have to" which is most likely when one of the

children has an out-of-town sporting event. The language of *having to go out* perhaps suggests that Kim and Grant might feel social pressure to take part in events with family and friends.

My personal aside: A mother's perspective. Like the child/teen and parent participants in my study, I too feel that going to a restaurant to enjoy a family meal is often very stressful. As a mother I know I must model and support Ashley with food allergy advocacy strategies; however, restaurant staff's understanding of food allergies and their willingness and/or ability to communicate and accommodate seem to determine a positive or negative family experience.

Family travel. For Barb, the "hardest part" about having a child with food allergies is "travelling—number one absolute." For a family that is involved in winter sports, it means they are often away Friday night to Sunday "which means [Barb] need[s] meals for [Robyn] for pretty much that whole time." Barb detailed the planning and preparation required for her family to be on the road so frequently:

We always stay at a hotel that has a suite. If we can't stay at a hotel that has a suite, then we have to ask to use the staff kitchen to warm up chili or shepherd's pie or whatever it is that we bring. And sometimes if we're staying in a higher end hotel, I'll call ahead and talk to the chef and see if we can make a dinner for her. It's almost always fish and a potato or fish and French fries.

Barb shared that "if" she has "enough time" she will prepare "meals for everybody." One of the few restaurants the family can go to is Swiss Chalet, so if there happens to be a Swiss Chalet in the town they will go there "but there isn't always." Barb also shared that they can "sometimes go to Subway" and have a salad prepared for Robyn if Barb watches "with an eagle eye." This also requires a good deal of communication of needs as the ingredients have to be "fresh out of

the bag for her so that [they] don't have to worry about contamination of cheese." Although she highlighted these experiences, Barb said "typically" they bring their own meals.

Out-of-country travel presents its own unique challenges and requires a great deal of preparation as reported by the participants in my study. Megan shared that her family has travelled to Florida to visit relatives and found it "okay" because they "didn't have to stay in a hotel." She remarked that "buying all the food" was "kind of hard" because products are different than what she is used to in Canada. According to Diane, staying with family is the "only way [they] can do it" because they prepare all the meals, although she did speak of going to one restaurant that was "pretty amazing" in accommodating Megan. Diane did state that it was only because of the preplanning and communication strategies they put in place that they were able to go out. She reported that the most stressful part of the travel was the lack of support from the airline when they were flying home. Even though Diane had called ahead to confirm that Megan had a nut allergy and it was on her ticket, nuts were being served on the plane. As soon as she noticed nuts were being served. Diane spoke to the attendant. She was questioned and admonished by the flight attendant for not confirming once more with the front desk attendant. Diane said the experience was the "most embarrassing thing [she] ever, ever dealt with . . . it was absolutely horrible." Sadly this was not the first time Diane had trouble on a flight.

Staying "with family" when travelling has made it "so much easier" for Kim's immediate family to travel because they are able to buy and prepare their own food. When they do stay in hotels, they request a room with a fridge and bring food with them. Kim said that when on the road they "can always find a pizza place that's safe." When staying with family on an overseas trip was not an option, Kim rented a "flat" where they would be able to do their own cooking. The whole trip required "quite a bit of research" and preplanning around everything from the selection of an English-speaking country (so they could communicate worry-free) to the chosen airline (that does not serve any nut products on any of their flights), right down to a particular brand of ice cream (that would be available in a nearby store and safe for her son to have).

Kim's airline experience was positive when compared to Diane's—likely due in part to Kim's purposeful selection of an airline that does not serve "any nut products" on their flights. Regarding travel, Kim said she had called ahead to confirm and "they made an announcement before we got on the plane, they made an announcement when we got on the plane." She recalled that "here was also somebody with a banana allergy" so all passengers were asked to refrain from opening a banana on the flight. Although the airline did not serve "any nut products," some of the products did say "may contain traces of" so Kim and her children declined all food offers on the flight. She did say it was "hard" because "it's not all about food" all the time and that she "just want[s] to go and do stuff" and doesn't want to "have to worry about food." Despite not wanting to worry about food, it was a very real consideration that Kim did her best to address ahead of the trip. About researching food items, Kim said her brain was "spinning all the time" and stated:

Of course you have a list of products and then you go to the store and you can't find them. So basically . . . we had pasta, we found these pizzas, they weren't frozen, more like a fresh pizza on an already cooked crust but it was all assembled. So we ate a lot of that . . . really we didn't go for the food.

Kim made sure to bring snacks like "Bear Paws" cookies from home to augment the lunches they packed to take on day-trips. This safe-care strategy helped to reduce concern so the family could

enjoy their vacation. Even though Kim had spent an extensive amount of time researching and preparing for the trip, she was still worried and recounted her first night of the trip:

I went to sleep. I woke up. I had a dream that I couldn't do it, we had to get on a plane and go back. How did I think we could do this with the food and everything like that (I don't know why)? And I woke up just super-panicked, thought I was going to be sick. Kim did say everything worked out "fine" and that she would "do it again" because "it's worth the travel." She remarked, "do you buy everything nut free, no you don't . . . there's no nut-free bread, you just buy bread that doesn't say 'may contain traces of nuts' or whatever." Although the family had a positive experience, it was an emotional journey for Kim.

Not all parents in my study feel like travel is an option for their children. Barb said her "biggest sadness" will be that Robyn will have "limitations." She explained further:

I am very sad . . . she's not going to be that kid with the Eurorail pass backpacking through Europe footloose and fancy free for 4 months. There are places she's just not going to be able to travel. And she doesn't really know that yet, but I do.

The application of safe-care strategies becomes more challenging for individuals with food allergies who want to travel. As is the case in Barb's backpacking example, individuals with food allergies are at times confronted with choices that push their allergy comfort boundaries.

"The Purse" as Symbolic of the Transfer of Responsibility

Eight of the 10 study participants spoke about the use of a purse as a successful strategy for transporting life-saving medication and/or safe food items when outside of the home. Kim thought that "a purse is a little easier [for a girl] to carry around" than a boy and noted her son typically carries his medication in his backpack or his lunch bag. Tina remarked that one of her female high school students carries an EpiPen® in her purse. It seemed to me that both Diane

and Grant viewed the acquisition of the purse almost as a rite of passage for their daughter, signaling somewhat of an unofficial transfer of responsibility for care. Diane spoke of the shopping trip to buy Megan's "funky brown leather purse," and Grant referred to Megan's maturity when he called her a "young lady with a purse."

Currently in grade 7, Robyn could not recall when she transitioned from a character fanny pack to a purse to carry her multiple medications. Both Ashley and Megan talked about beginning to carry their purses in grades 6 and 7 respectively. Ashley stated that it is "much less embarrassing" to carry a purse than the "big clunky black thing" she previously used to carry her EpiPens® and Benadryl®. She also mentioned her purse is "just so it's not obvious," which was similar to Grant's comments about Megan's purse as able to "conceal" her medications. During Diane's interview she discussed Megan's purse as a place to store items required to ensure inclusion in school-related activities. For example, when Megan's intermediate class went on an overnight school trip, the attraction venue staff refused to accommodate her food allergies, so Diane told Megan to "shove your purse full of food" so that she would not be the only person without food in front of her. Diane also recounted Megan's purse coming in handy when Diane had to provide latex-free condoms so that Megan would be able to participate in a class lesson about sexual health in the grade 9 Healthy Active Living Education course. In all of these instances, not only was the purse helpful in keeping private items free from public viewing but also in allowing the young ladies to have some responsibility for their self-care.

It was interesting to learn that although both Ashley and Megan carry their purses with them to high school, they do not always have them on their person. When asked if she carried her purse with her at all times, Megan's tone of voice seemed to indicate to me her surprise at her own "no, I don't" response. Megan reported that during the lunch hour when she was walking around with her friends she preferred to keep her purse in her backpack in her locker. When I asked what she would do if she needed her purse, Megan replied "I don't know . . . I haven't really thought of that yet." I had a similar response from Ashley when I asked her if there were times during the school day when she did not carry her purse with her. She said if she was "just walking to the bathroom" or "walking around at lunch" she would not necessarily have it on her because "it's very heavy." Ashley justified her decision suggesting that in the small school she attends she could quickly get to her locker, then added "but that's no excuse for not carrying it." Both girls' responses gave me the impression that they know and understand why they should have their medication (and hence their purses) with them at all times, but their reported actions did not always seem to align with what they know to be the right or responsible thing to do.

Mothers, Barb and Kim discussed carrying their respective children's medications in their own purses. Barb explained that she carries two of Robyn's EpiPens® in her own purse "in case she's forgotten them," which was similar to Kim's explanation for keeping two of her son's EpiPens® in her purse for when "he doesn't bring something." Kim also talked about having liquid Benadryl® and Claritin® capsules in her purse if "anybody" needs them. She did say "eventually, I'm not going to carry it in my purse . . . but why not" which might suggest that as a wife and mother, she feels a sense of responsibility for her family members' well-being. At this point in time, having the medication with her for anybody's use seems to outweigh the risks of not having access to potentially life-saving allergy medication for someone when needed.

Summary of Responsibility: Rules, Routines, and Safe-Care Strategies

Just like the first theme in this chapter built a foundation for understanding *how* allergy identity is constructed and reconstructed, this second theme around responsibility serves to provide the reader with a *context* for understanding child/teen and parent participants' daily life

with a serious food allergy. I began the thematic discussion using Robyn's "we make rules" statement to call attention to the rules, routines, and strategies that provide structure to and guide the everyday decisions and actions of individuals and families dealing with food allergies. I highlighted key elimination, avoidance, substitution, and inclusion strategies that are in place in homes to keep the child/teen participants in my study safe. As well, I described the actual safecare food preparation procedures and processes that study participants noted have become part of their normal routines. Then, the application of safe-care strategies to new contexts outside of the home illustrated how preparation and trust are essential aspects to consider when trying new things. I concluded the thematic discussion of responsibility with an examination of the use of the purse as a supportive tool in the transfer and acceptance of responsibility for food allergy. I feel it important to explain that I made minimal reference to school experiences in the discussion around the rules, routines, and safe-care strategies families use in their day-to-day lives for two reasons: (a) to focus on the description of the needs and strategies used by child/teen and parent participants, and (b) to emphasize why in the forthcoming themes, communication seems essential and ethical disconnects are perhaps so concerning.

"There are some things you learn best in calm, and some in storm" (Cather, 1915, p. 378).

Labels and Labelling

During all of the interviews, I was attuned to the language participants used to discuss allergy-related labels and labelling. Perhaps the most obvious aspect as it pertains to food allergy is the importance of reading labels on grocery products. Being labeled or using allergyrelationship identifiers has both helpful and harmful elements which I review in the subsections below. I conclude the thematic discussion of labels and labelling with an exploration of medical identifying jewellry as a missing label.

Reading Labels

Diane talked openly about how she "used to hate" grocery shopping because it would often be a "2-hour" experience reading "label after label," usually with one or more children in tow. Familiarity is a strategy Diane now uses to be "pretty confident" in what she purchases one store, same brands, and little deviation from the list. She admitted that if she has "to go to another grocery store, anxiety through the roof" because she doesn't "know where anything is" and Megan's allergy restrictions require Diane to locate familiar "brands." Kim expressed a similar sentiment when she stated, "you know your store and you know what you can buy" and as a result she doesn't find "grocery shopping a huge challenge." Kim shared that "once in a while" she would "love to" be able to purchase something from the "bakery" or buy the prepared "veggie trays or fruit trays," but she doesn't because of the "may contain traces" label. Grant advised that while he does not read ingredient labels "every time" for the products he purchases regularly, he advised "you've got to read it once in a while because they change the ingredients."

Ashley said that she always reads product labels on food items and personal hygiene items like makeup or creams because "you never know if it's going to change." One positive aspect of having an allergy, she joked, is that her "literacy skills have improved because [she's] really good at skim reading . . . because [she's] not going to stand in the grocery store aisle reading a label for 10 minutes." Megan also stated that she reads labels "all the time, especially if it's something new." Megan shared that she used to "really like" a particular brand of ketchup-flavoured "mini rice cakes" and "one time [she] was reading the label . . . and it said milk" and she could no longer enjoy the snack. Megan stated that "upset" her because "that's one more thing [she] can't eat," noting something similar happened with her "favourite kind" of Lay's ketchup chips. She clarified "they didn't have milk in them before . . . and then they were putting milk in them."

Kim shared during her interview that although almost everything she makes is homemade, she was actively looking for a prepackaged nut-free granola snack bar that she could throw in her bag just to have. She was able to find an online Canadian company that manufactures a product that suited her needs. As well, she was able to find a nut-free trail mix, pumpkin seeds, and flax seeds that were not "processed on equipment" that may have come in contact with nut products. Kim was the only participant in my study to mention online shopping for safe food products and said "it's really exciting" when you find something you can purchase. Kim also discussed the importance of clarifying the language used to identify allergens when shopping. She explained that she once went to a bakery that claimed to be "peanut-free but not nut-free" which prompted her to inquire. The employee explained that while their ingredients are nut-free, their products are manufactured in a facility that does have a "may contain traces of nuts" warning, so they cannot guarantee that their baked goods have not come in contact with nuts. As a precaution, the bakery does triple-wash the equipment that "may contain traces of nuts" before running their own product through the machines, which does give customers the choice whether or not they wish to consume the baked goods. Kim explained, "If I go to my mom's and she had peanut butter for breakfast and it was on the knife and it didn't come off in the dishwasher well enough, like it's the same kind of idea, right?"

Being Labelled

A few participants in my study used labels as naming tools to identify or describe relationships with allergy. Kim used the self-labelling term "allergy-parent" when sharing her appreciation for a food allergy advocacy group that organizes nut-reduced social events (see aforementioned *Opportunity*). Kim's usage of "allergy-parent" seemed to me to be positive in that it evoked a sense of kinship and trust that resulted from the knowledge that others had experienced or understood food allergy-related parenting experiences. Robyn also self-labelled when she included herself in the discussion of what "teachers are taught about the allergy kids and what to do with them." She remarked that she found it "funny" that she would be walking down the hall at school and teachers whom she did not know would be saying, "hi Robyn" in the hallways. Further, Robyn recognized that this likely occurred because the teachers would have seen her picture on the allergy information sheets posted in various areas in her school. Robyn shared a unique perspective on her allergies—she thought that if she didn't have allergies she "might even be a nobody" and that "everybody kind of knows who [she is] by [her] allergies."

Allergy identifiers used by some participants in my study may not always have positive connotations or associations. Parents Grant and Barb used the term "allergy kids" in their respective conversations about "isolating" children who had food allergies during the school lunch hour and the "hardest part" about having a child with food allergies being travel (see aforementioned *Restaurants and Family Travel*). It seems that both of these examples may address the parents' underlying desire for their children to be fully included in everyday life events like enjoying a meal with peers at school or with family while on the road. Angela was the only other participant to use the term "allergy kid" and, interestingly, only one of her three uses seemed to have a negative association—when she spoke of individuals who intentionally "tease" or threaten students with food allergies for their own enjoyment. The other two instances where Angela used "allergy kid" were more pragmatic—to identify the "allergy kid" was "fooled" by a food label despite being very aware of allergen labelling on grocery products. I

explored how labels focused on *people* are used to: identify self or others, explain positive or negative relationships with allergy, and communicate allergy-relationship information to others.

Helpful Labels

In this section, I consider how the labelling of *places* and *things* associated with allergy can be helpful in communicating to individuals with allergies and to others who care for them. As I have previously called attention to labelling strategies in the home (see *Responsibility: Rules, Routines, and Safe-Care Strategies*), here I focus on school-related allergen labelling.

Safe space signage. There were two kinds of signs that participants reported are used in schools to communicate information about safe spaces for students with allergies—signs that attempt to exclude food and signs that attempt to include people. Ashley remarked that all of her classrooms have "allergy aware signs up so not a lot of eating goes on in [her] classrooms." She thought that this respected teachers and classmates because "it's just not a place where you eat." Similarly, Kim shared that her son's high school also posted the classroom doors of any student with an allergy. Kim recalled the signs reading "no food allowed—allergies" which she appreciated because Kim didn't think students "need to be eating in class." As a secondary school teacher, Tina's experience with allergy signage in schools was similar, noting that "nutfree zone" signs are however more prominent in elementary schools. In addition to food allergy signs in her high school, Tina stated that "scent-free" signs are becoming more common, though in vice-principal Carolyn's board, this did not seem to be the case. Carolyn shared an experience that when at a professional learning session a teacher who was "very allergic to scents walked into the room, swelled up, and started wheezing." In her interview, Carolyn was notably dismayed that she was not aware that her board had a "scent-free policy" and that "this poor teacher who has been trying so hard to get the board to support her in this doesn't even have

signs in her own school." Although the intent of allergy signage is to be helpful, Diane expressed her frustration with the labeled "allergy room" in her daughter's high school. Diane stated that she "hates" that it is a "separate" room located near the back of the school "segregated" from the rest of the students. While she understands that the school has to create a "place for them," Diane shared that Megan "doesn't go there."

Buckets and desks. Although Angela was "not sure" what the cleaning protocol is in her current school, she shared what she observed in a previous school with regards to cleaning the desks of students with life-threatening food allergies:

The custodian had a separate bucket for each child who had food allergies. The bucket was exclusively used to clean that child's desk. So it's not like they would wipe everybody's table and then wipe the allergy kid's table. So everyone's table got wiped with the common rag but the child who has the food allergy, they had their own bucket with their own rag just for them.

Angela knew for certain that the "buckets even had kids' names on them so the custodian would know," and she surmised that the desks "must have been labeled somehow." While Angela appreciated the care taken by this custodian, she noted that learning does not just happen at students' designated seats and that cleaning does need to happen more frequently during the school day. She explained that the kids eat and work at the same tables throughout the day.

Labels as Harmful

Making public the offending allergens of individuals with life-threatening food allergies can increase the vulnerability and the likelihood of exclusion, teasing, and bullying behaviours being directed at them. In the two subsections that follow, I share participant experiences and stories that portray allergy labels as harmful to the physical, social, and emotional well-being of individuals with food allergies and their families.

Teasing. When asked if she had ever been teased because of her allergies, Robyn replied "not once," but quickly rescinded her response saying that "just this year" one of her friend's older brothers called her "allergy—just as a joke." Although Robyn said it "doesn't bother [her]," I had an overwhelming sense during the interview that it just *might* bother her. The quick clarifying statement, combined with the explanation "he doesn't think it's funny—he kind of just says it" and a barely audible laugh, suggested to me that Robyn did not appreciate the "much older" boy calling her this (see also *Target* forthcoming).

While Megan could not recall ever being teased about her allergies, Ashley said she is bugged "all the time" and didn't "even know where to start" to list all the times when it has happened. She said the "whole allergic to everything," "aren't you allergic to air," or "aren't you allergic to water" are common phrases directed at her. Ashley admitted that "sometimes it hurts when people keep going" and feels that there are "a lot of stereotypes around nuts . . . or just allergies in general" which adds to "people not taking it seriously." She explained that many of the "shows that [she] used to watch when [she] was little" would stereotype "nerds having allergies." She recalled characters on these television programs would be the "kids with the big glasses and braces and the buck teeth and their mom [would] pack them a special lunch because they're allergic to peanut butter." In her interview, Ashley talked about how she feels television advertisers have increased awareness of allergies but at the expense of allergy sufferers not being taken seriously. She shared:

There's that EpiPen® commercial "blue to the sky and orange to the thigh." Every time I say that I have allergies and I say do you know how to use an EpiPen®, everyone just starts off with the song or the rhyme or whatever . . . But I think that they think it's kind

of a joke, that they don't take it seriously because there's a stupid commercial. . . . I get the whole marketing and advertising thing—that they need to make it something catchy, but people don't take it seriously.

Ashley continued with a suggestion to have the "people with allergies . . . market allergies" so that others might see how serious the issue is.

My personal aside. During Ashley's interview it seemed to me, as her mother, that she felt there was a relationship between the negative portrayal of youth with food allergies in mainstream media and the belief by some that the ill-treatment of individuals with food allergies is acceptable. It is troubling to me to think that young people may be encouraged to target, tease, or bully individuals who live with an invisible life-threatening allergic disease.

Target. Robyn stated that when she was in grade 6, she "had an experience" where a "new kid who didn't get [her] allergies" was "dangling allergens over [her] head." She said that it was not the only time this had happened, but she did share that it was only ever boys who bothered her in this way, though she made it clear that other "guys stood up for [her] too." Robyn thought that the move to an all-girls school this year might alleviate this concern for her, saying "I don't have to worry about guys anymore."

Ashley thought that the worst times for her might have been in grades 7 and 8 when the "guys think they're cool by making fun of girls and teasing them." She shared that her peers would "make fun of [her]," "threaten [her] with peanut butter or nuts," or "just say they're going to pour peanut butter on [her]. " Although the verbal and food threats Ashley received did not result in an anaphylactic reaction, these instances were emotionally challenging for her. Angela recounted the horrific story of a young boy who was not so lucky. She shared that a student from a nearby school, who, when "on the way home," was "chased by some kids" who "had peanut butter and they put it on him and he did have a reaction." The perpetrators, who Angela recalls

were no older than grade 6, "thought that it would be a fun thing to torment this kid." The boy was hospitalized, and Angela believes that the parents were "absolutely outraged" as a result of the assault. Although the incident did not "happen on school grounds," the parents ended up "pull[ing] him out of that school" where he had previously attended with his attackers. Angela could not recall hearing anything further about what had happened after the incident, either to any of the assailants or to the boy who was the target.

MedicAlert®: The Missing Label

Robyn was the only participant in my study who wore a *visible* piece of MedicAlert® jewellry during her interview—a necklace. Neither Ashley nor Megan were wearing a traditional MedicAlert® bracelet or necklace during their interviews. When asked, Ashley said she stopped wearing her bracelet between the ages of 10 and 12 because it would "always break." Megan noted that while she did have a bracelet, she didn't wear it because it needed "to be updated." Kim spoke briefly during her interview of her son's MedicAlert® but did not specify if it was a bracelet, a necklace, or another form of identification. Likewise, Kim did not indicate whether or not her son actually wore the medical identifying jewellry. Grant remarked that the bracelets of the past were "ugly" and felt that he and Diane might have stopped renewing the "yearly" update since Megan was never wearing her bracelet anyway. He talked about how at Megan's school there is "another EpiPen®" in the office; he noted school staff is "fully aware" of his daughter's allergies, and commented that he and Diane "do put some trust in them [school staff]" so they were okay with Megan not wearing the bracelet "for now."

Although Tina had been advised to wear a MedicAlert® bracelet for her peanut allergies, she said, "I just don't feel like I'm allergic enough . . . to wear a bracelet." When asked if current or former students with food allergies wore MedicAlert® bracelets, she remarked that she has had "a few students over the years with MedicAlert® bracelets . . . but you don't tend to see it much." She continued by saying that previously "you could tell [who had food allergies] by that MedicAlert® bracelet" and she commented that "people may not even know what that is anymore." Carolyn's experience as an administrator supports Tina's view that the popularity of the MedicAlert® bracelets might be declining. During her interview, Carolyn seemed genuinely surprised that she could not recall "any child" at her school who wore medical identification jewellry.

Summary of Labels and Labelling

By illuminating language usage in this third theme, labels and labelling, the reader can gain a deeper insight into the thoughts, values, beliefs and behaviours of the participants in my study (Vygotsky, 1934/2012; see also Glesne, 2011; Monteath & Cooper, 1997). In this section, I discussed label reading as a time-consuming protective strategy that requires attention to detail, specifically around allergen warnings. Although I could have explored being labeled (by one's self or others) as an aspect of identity in the first theme, I felt it necessary to consider the actual words and meanings associated with the labels ascribed to people. Next, I shared how labels used in schools with the intent to include do not always do so, thereby creating tension. I discussed how being labeled as having a food allergy can increase risk and harm for individuals who are teased and targeted. I closed the thematic discussion of labels and labelling with a look to how the absence of medical identifying jewellry may be indicative of a disappearing label.

"The act of labeling, however well-intentioned, creates a stigma and any act of stigmatization is an act of violence" (Monteath & Cooper, 1997, p. 112).

Communicating Allergy

All of the participants in my research study addressed ways that allergy is communicated in their personal and educational lives. I begin this theme with a discussion of communication for education and advocacy. Next I share home–school communication strategies that include written, oral, and physical approaches. I continue by detailing select emergent issues that address food policy communication within a school community context. Open dialogue between teens and their parents, sometimes around uncomfortable truths, follows. I close the thematic discussion with a look at the cell phone as an effective communication tool.

Communicating for Understanding

The participants in my study shared that they believe communication is critical to promote understanding and awareness of food allergies and anaphylaxis. Here I share examples of communication and advocacy strategies that seem to have worked to support children with food allergies and another that resulted in a relationship breakdown.

Medical professionals. When Barb was trying to determine the cause of Robyn's eczema, hives, stomach upset, colic, and bloody stools, Barb's physician "kept telling [her] that the proteins didn't make it through [her] milk." When Robyn was later diagnosed with multiple food allergies, Barb had a frank conversation with her physician:

I sat him down after, you know, when things became obvious with Robyn and I said, "you need to learn from this experience—you need to recognize that you were wrong in that so that if it happens to someone else, it won't take them three months to figure it out."

Education and advocacy was also a part of Kim's experience. When her son had his first allergic reaction, he was not immediately prescribed epinephrine. Instead the family doctor advised "just

avoid it" and shared that his own son was allergic to fish and avoidance worked for their family. Unsatisfied with the physician's response, Kim "eventually" got an EpiPen® but she had to "ask" for it, as well as for formal allergy testing. Interestingly, Kim received her son's confirmatory allergy results by phone from the allergist's secretary, offering time and distance as explanation as to why they were not required to make the long trip to receive results.

Robyn shared that she was "nervous" to meet her new doctor in person because she had previously communicated with the physician only via video-conferencing. When she eventually met her allergist in person, Robyn claimed she "didn't really know her" and didn't "want a needle from her" either. It seems that while communication technologies in this instance saved time and travel, rapport still needed to be established when a face-to-face appointment occurred.

Family and friends. Advocacy and awareness seem to be a constant in the lives of the child/teen and parent participants in my study. Robyn was "scared that none of [her] friends would understand" her allergies and "didn't even tell anybody, except the teachers at first" because she did not want to be known only for her allergies. For Ashley, the ignorance or lack of consideration on the part of others is frustrating. She shared that even students who know her and know she has life-threatening allergies bring peanut butter products to school and "start eating" right beside her. She admits that she is "uncomfortable" self-advocating because she does not "want the attention" to be on her.

Barb is not convinced that her father-in-law really understands the difference between "his wife's sensitivities and Robyn's allergies," remarking that Robyn has had to say to her grandfather, "I can't have that" and even then he questions "not even just a little bit?" Kim shared that an extended family member often "forgets" to remove nut products from view or serves items that Kim's son cannot have. As such, Kim and her son have established a "follow my lead" rule whereby Kim's son can take a food item if Kim herself has already taken it. Kim said this is a good strategy because she's not going to "scream out there's nuts in that." Similarly, Ashley finds it "very annoying" when food items containing nuts show up at family dinners. She perceives this as a lack of respect and stated, "they've known me all my life and they still don't care," explaining this affects her relationships with extended family members.

Communication breakdown: The "arsenic" sippy cup. Barb recounted a story where, despite her very best efforts at communicating her then 2-and-a-half-year-old daughter Robyn's allergy needs with her child care provider, the arrangement "worked really well, until it didn't." In the beginning, one-year-old Robyn was the only child being cared for by a woman (in the woman's own home) who had "severe allergies" herself. Due to Robyn's extensive food allergies to eggs, milk, soy, wheat, lentils, peas, chickpeas, nuts, and bananas, food preparation was kept "simple" for the babysitter. When the woman eventually asked Barb about bringing other children into the home daycare, she and Barb met to establish new rules, one of which was that the other children "would only have milk when they're in the high chair" due to the severity of Robyn's milk allergy. One day when Barb was picking Robyn up, she noticed Robyn and another young child had "identical" sippy cups but Robyn's had "rice milk in it and the other kid's had real milk in it." Barb said, "The scariest thing about that situation was that she [the babysitter] thought she had it under control," telling Barb that the "kids know" the difference. During the interview Barb remarked that "she just couldn't believe it" and that "it was crazy dangerous ... like having a sippy cup full of arsenic." Years later she is "still so mad" at the former babysitter for "trusting the 2-and-a-half-year-olds to keep their sippy cups straight, even though they looked identical." The situation resulted in a loss of trust and friendship and in part contributed to Barb's decision to take a reduced schedule at work.

My personal aside: A parent's perspective on childcare. For parents who have an infant or a child with life-threatening food allergies, the return to work following a parental leave is challenging. Over 15 years ago when I was searching for a suitable childcare environment, I found that the centres I approached were unable (or perhaps unwilling) to accommodate Ashley. A trusted family member who understood Ashley's allergy needs cared for her in my home.

Home–School Allergy Communication

As children with food allergies enter the school system, a gradual release and some transfer of responsibility occurs in two simultaneous ways—from parent to child and from parent to the educators. In this section I detail how home–school communication strategies change as the children with food allergies transition from primary to secondary school.

Required forms. Mothers Diane and Kim talked about the different kinds of paperwork that parents of children with food allergies have to fill out each school year. In Diane's discussion of the Epipen® form and the bus form, she said she "love[s] a small community because everybody's aware of it," which seemed to suggest the "required forms" were not used as the primary method of communicating allergy. Kim made a similar remark when she shared how in a "small school" most people "know your child to a certain extent," largely due to the student "posters in the staff room with everybody's picture, their allergies, and the EpiPen® stuck to it." In addition to the forms for the school and for the bus company, Kim also prepared an allergy information sheet for her son's bus driver. Regarding forms in high school, Kim remarked that "it's just too bad it couldn't be from grade 9 to 12 . . . like one shot," sharing that the forms aren't the problem, it's that "you've got to haul people to the doctor's" ideally between "June and September" to get the forms completed "every year." It was interesting to me that the two teachers in my study, Angela and Tina, did not discuss any of the official forms required by

their respective boards of education; however Tina did note that at her previous school she "[thought] there may have been a binder in the staff room" with information about students' allergies. Tina's tentative statement seemed to suggest that the binder was not in frequent use and that other communication strategies are more heavily relied on by secondary school staff.

School start-up meetings. All three mothers in my study reported going into their child's elementary school before classes started each year to discuss their child's allergies with the school principal and the teacher(s) if they also happened to be there. The purpose, Kim noted, was to "meet the teacher" and "just talk" about her son's allergies. Diane shared that when Megan was starting school she made two separate appointments—one to speak with the principal and another with the kindergarten teacher. At the meetings, Diane provided an introductory letter that she asked educators to distribute to the students in Megan's class (see next section *Letters Home*). Although not directly stated, it seemed Kim and Diane attended introductory meetings without their children. It is interesting to me, as a parent, that none of the girls talked about attending such meetings, although I know Ashley has been present at some.

Like Kim and Diane, Barb has also gone into her daughter's elementary schools to speak with Robyn's teachers about how each of her food allergies manifests. Barb explained that it has been challenging at times to ensure that educators understand Robyn's allergies:

You can imagine when I'm telling people, Robyn has allergies to these foods and then she has her fruit and vegetable allergies which are not going to be anaphylactic but are still going to make her really uncomfortable . . . Then, she's got wheat which she is just sensitive to, but if she has too much, her throat is going to close up and she's going to start getting food stuck because she has EoE. It's information overload because they don't know how to process all those levels of sensitivity—like she can cheat on wheat about once a month and not suffer any consequences. . . . It's important for teachers to know that she can have food impaction. . . . If she has a little bit of wheat she's not going to go anaphylactic but if she has a little bit of egg, she might.

Now that Robyn is in grade 7 and has multiple teachers throughout the day, Barb said that it is a "long conversation to have with a lot of different people," noting however that not all of Robyn's teachers have responded to Barb's initial contact.

As a secondary educator, Tina does not recall having had a school start-up meeting with a parent of a student with food allergies, noting the administrative team usually takes care of that:

They're pretty diligent about meeting the grade 9s, knowing what their needs are, and addressing them before they arrive at school. So I think hopefully they would have

prepared them for dealing with some of the challenges in terms of where to eat. It seems that school start-up meetings between parents of children with food allergies and educators are more likely to occur in the elementary years or at key school transition times.

Letters home. There were two types of school start-up letters that the mothers talked about in their interviews. The first letter introduces the child with allergies to other children and families. The second letter, addressed to the teacher, serves either as an introduction or as a follow up to in-person meetings by providing, in writing, specific allergy details and contact information. A third type of letter that is situation specific (not school start-up related) was also mentioned but will be shared in context in the forthcoming *Ethical Dis/connect* theme.

Kim said that every year the school would send a "there's a child in your child's class" letter to inform other families about students with food allergies. She felt "fortunate that all through school there was another child" in her son's class who also had a peanut allergy, so "at least [he wasn't] the only one." Even though all of the students in her son's class knew he had a nut allergy, I sensed from her interview that Kim appreciated the authority of the letter sent by the principal and that her son was not specifically identified as different.

As an elementary school teacher, Angela talked about a "really nice letter" that she has seen "a couple of times" that is written by a parent but from the perspective of a child with food allergies. Angela said it typically introduces the child and mentions that s/he is "excited to start kindergarten" but it would "really help me to be safe during the day" if you "wouldn't mind enjoying your nut things at home and really washing your face if you have peanut butter toast in the morning." Angela feels that this approach is much more "powerful" than a note from the principal saying not to bring nut products to school.

When Megan was starting kindergarten, Diane did prepare a letter for school staff to distribute on the first day of school to the other students in Megan's class. The note, written from Megan's perspective, introduced Megan, shared her food allergies, and ended with a respectful request to other families:

Could you please make sure that if you are having peanut butter, cereal with milk, [or] eggs, could you please wash your hands and mouth because in JK all the kids play with toys . . . but especially peanut butter, with the oils, can get on other toys and if Megan touches it, she will react.

For impact, at the end of the letter, Diane added "it's not fun being stuck with a needle and driving to the hospital in an ambulance." She felt that "most of the parents were absolutely amazing" about Megan's allergies, but "one parent just didn't get it." Diane talked about having to clarify that all she was asking was for the parent to "wipe [his/her] kid's hands and face before they come in [to school], especially if they have peanut butter." Diane admitted that she stopped

sending these types of letters when Megan was in grade 1 or 2 because it was "the same core [group] of kids" in Megan's class each year.

The second type of information-sharing letter helps communicate individual allergy information to teachers. Barb said that this year, she sent a "very long email to Robyn's teachers" detailing "everything that they could possibly want to know" about Robyn's allergies. Even though she had previously had conversations with two of Robyn's teachers before school started, she felt that individual emails inviting the teachers to "call [her] at any time" were important. Barb admitted that one teacher did not even "acknowledge receipt" of the email.

Parent presence. Kim spoke at length about the amount of time that she spent volunteering in her son's elementary school and stated that volunteering gave her a "familiarity with people" in the school. One of the volunteer tasks that Kim took on was preparing allergy information sheets for every student in the school who had allergies—a task that had been passed on to her from another mother. She expressed gratitude to the other parents of children with allergies who "made their way through before" her because "things were set up . . . fairly well." While the allergy information sheets were prepared by the volunteer parents, the school requested the family provide an EpiPen® for the classroom and the office. Kim remarked that the "bad thing about the office was that at one point . . . it was locked in a cupboard" which she thought would not be helpful in an emergency (see more in *Ethical Dis/connect* forthcoming).

Kim also volunteered for "hot dog day" in her children's school "for many years" and explained that for a few years there were "two children that had sesame seed allergies and then one child [who] had a milk allergy." She talked about preparing "separate wieners" for the child with the milk allergy and going through the one package of buns to "check for sesame seeds [to]

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make sure they were okay." Kim remarked "I could not trust somebody, you know, to do that for my kid, for a hot dog" but noted that others did put their trust in the volunteer mothers.

In developing a "rapport" with school personnel, Kim felt comfortable bringing to a teacher's attention a concern she had about Halloween spider cupcakes that had M&M's® candies for the eyes. Kim explained that "just [be]cause it's a plain M&M, it doesn't mean there's not a peanut in it. It's like a Glosette raisin, and a Glosette peanut. Like how do you know?" Kim and the teacher ended up wrapping the individual cupcakes and sending them home with the students, but she does recall that the cupcake baker, who was a friend of Kim's, was "upset" that the teacher "didn't let [the students] eat them."

When Barb's request to have milk removed from Robyn's kindergarten classroom was denied, she felt that her "only choice was to become a lunch monitor" in her daughter's classroom—something that she was able to do as a result of her employer's willingness to accommodate a 70% work schedule. Barb felt that Robyn had a very "intimidating first day" of school as a classmate, who had "just downed her entire chocolate milk and was obviously sick with the flu . . . turned around and threw up chocolate milk all over the floor and it splashed up all over [Robyn]." Barb shared that in school start-up meetings with Robyn's teacher she had talked about things like the "play scissors" not being "that same scissors that you're using to cut open yogurt tubes," but no one could have "predicted that that would have happened."

One year, on the weekend before school started, a student who was registered to begin kindergarten in Angela's class had a "near death experience with a cookie that had macadamia nuts in it." The mother of the student, who Angela recalled was "very nervous and cautious," did spend time in the classroom. Angela stated that she appreciated that the mom "was always keeping [her] abreast of things" pertaining to allergies, like reading the ingredients in nonfood items such as "lip chap." In terms of parental presence, Angela said it really depended on the severity of the child's allergy whether or not the parent would visit or volunteer in the classroom.

School days. When children with food allergies begin school, parents and educators are required to work together to ensure the safety and care of the children. For parents, this means thinking about how the rules and routines already established in the home can be used or adapted in the school environment. Diane worked with the administrator at Megan's school to determine where Megan would eat her lunch and ultimately Diane decided that she did not want Megan isolated in a room separated from her peers but that a separate table with an assigned friend would work. Diane recounted that they had only one incident during Megan's elementary years where yogurt was opened near her and it "splashed up" onto her face. Milk products were also one of Barb's concerns during Robyn's elementary school years. Like Diane, Barb also wanted Robyn to socialize with her friends during the lunch break. Given the chocolate milk incident on the first day of kindergarten (see previous section *Parent presence*), Barb and the teacher established a system whereby desks were separated approximately 3 inches apart in case of spilled milk. Anticipating and communicating strategies with teachers was something that Barb did right up to the end of Robyn's grade 6 year.

All three girls shared that they do not eat anything from their school cafeterias. Megan and Ashley said that they do not even go into the cafeteria at their respective schools. Robyn discussed two rules she abides by: "I can't eat anything if it didn't come from my lunch, unless mom approved it" and "I can't buy anything from the cafeteria." Ensuring she has enough food for the day and any after-school activities requires planning, preparation, and communication.

At times, a lack of forethought on the part of teachers has resulted in the girls being excluded from classroom activities. Robyn said that "most of the time" her teachers let her know

in advance that they will be taking part in a holiday activity involving food, such as cookie decorating at Christmas. When the teachers forget, however, Robyn "feels like [she] has nothing to do" in class that day. At Halloween, if teachers hand out candy to the students, Robyn has been called over and asked about her allergies. She stated that if there are no ingredients listed she would just say "no." Similarly, Megan said that if teachers bring in food items like cookies, she just doesn't have any, though she was quick to add, "I don't really feel bad about it or anything" which at the time of the interview made me wonder if she was really alright about it. Ashley was forthcoming about feeling left out in similar situations in early years. She shared:

When I was younger it probably bothered me more because I was a little kid and I didn't get to participate. Now as a high school student, more people just say no thanks because they just want to look healthy... So really, I just look cool (just kidding).

The addition of the "just kidding" remark seemed during the interview to add a little bit of humour to what seemed like a sensitive topic of conversation. What might seem like a quick confirmatory conversation for the teachers might have been perceived by one or more of the girls as being excluded from their peers as a result of a teacher lesson decision.

For educators, ensuring the needs of students with food allergies requires planning. Angela said that in the past she would use food in some of her lessons but she does not really do that anymore. She shared an example of her thinking from a time when she had a student in her class who was severely allergic to tree nuts:

That affected whether or not I brought in acorns or pinecones, although it wasn't a thing to be eaten, I thought, well if she's allergic to tree nuts, like an acorn, that's a tree nut right? Or pinecones with the seeds in there—maybe that's dangerous to her too. So those were things that I didn't include in what we did. We didn't bring them in, we didn't collect them, we didn't use them as math counters or anything like that

although it wasn't food, I thought there was a possibility for her having a reaction. Angela was adamant that if there was an activity "where a child couldn't be included, [she] would prefer not to do it, than to exclude someone" stating "that just wouldn't be right."

Food-related activities in the secondary classroom seem to be more social than lesson based. Tina has in the past held potluck lunches for her students but would always call attention to peanut allergies in particular because of her own allergy. If she had students in her class with other food allergies, she would mention those as well. Tina shared that by communicating with her students and planning ahead, most students would participate. For special occasions like Thanksgiving, Tina has previously purchased and brought her students cakes or pies as a treat. She would always read the labels and keep the students informed. Further, Tina shared that she tells students, "there's no peanuts in here but it is made in a facility that does have nuts, so if you are worried, do not eat it" and usually any student who has a concern talks to her. Tina did say that she does keep a box of mini chocolate bars in her desk that are made in a peanut-free facility just as a backup for any student who might not want to have a piece of cake or pie.

As an administrator, Carolyn was often involved in activity planning at her school. She recalled once when the school was planning a carnival, they wanted to rent a popcorn machine, but because the company could not "guarantee that the oil was safe" for students with nut allergies, they rented the "candy floss" and "snow-cone" machines instead. I sensed during her interview that ensuring equitable access to all aspects of school life was important to Carolyn.

Field trips. For the parents in my study, field trips were activities for which they tried to make themselves available to attend. Barb's flexible work schedule allowed her to accompany Robyn during her early school years. Grant commented that he or Diane would attend "as much

as possible" when Megan was "really young," but now that she "doesn't want her mom or dad there" they try to give her some independence. Kim acknowledged that both she and her husband have, at different times, chaperoned school trips so their son could participate with his peers. Even when they were not selected to chaperone the immediate overnight trips, they were always welcomed to attend if they covered the cost of their accommodations. Kim did share that when her son was in grade 12, he did not participate in an out-of-country school trip and was "bitter" that he could not attend. It was interesting that none of the children or educator participants discussed in their interviews parents as chaperones on field trips.

Ashley acknowledged that school field trips are "really hard" for her because the unknown environments do not always feel "safe." She shared that even though people are warned and "everybody knows not to eat" nut products on field trips, it is very "intense" for her, noting "it's all forces out" on a field trip. It seemed to me that the level of vigilance required to participate and enjoy school trips can be overwhelming for Ashley. She shared that her participation depends on the itinerary, the proximity to a hospital, and the other students who are attending. Ashley admitted that sometimes she just says she can't go because "it's just easier that way" for herself and the teachers. She stated that the teachers probably "get a sigh of relief" thinking that they "don't have to be so worried about this."

When overnight field trip opportunities have come up, it was "major" communication and preparation that allowed Megan to participate. Diane outlined her interactions with the "amazing" teachers:

I emailed them saying obviously I have concerns. I am not saying "no" to Megan going, so can we sit down? On all these trips, all the teachers that were going were at that

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meeting and we all discussed her food allergies and what the food plan was for the other kids . . . so I would cook something similar to what they were serving.

Megan and Diane do a "big grocery shop" and make all of the meals that Megan will require for the duration of the school trip. They try to "make it all the same" meals as what her classmates will be eating and include safe snacks and treats as well. Megan spoke of taking a "cooler and a dry foods bag" and just taking out what she needs for each meal or activity. Diane shared that it was important for Megan to have access to a microwave either in the room or in a common area where the group was staying so Megan could heat her meals if needed. In preparing for an endof-year camping trip, Diane made sure to contact the resort staff to find out the daily menu so that Diane could prepare and label each meal with Megan's name, school, day, and meal. Diane felt "very confident" in this process and the teacher who ensured that anytime staff are heating up Megan's meals "I'll be there to watch" to ensure there was no cross-contamination. This strategy has allowed Megan to participate in several trips with her class.

School-related social functions. School functions such as athletic banquets or semiformal dances present their own unique challenges for students with life-threatening food allergies. Grant talked about how Megan was invited to her school's athletic banquet dinner and awards ceremony because she had played on a school sports team. Grant shared that "she did go, but she couldn't eat the meal" and noted that Megan "gets embarrassed" by situations like this. When asked about this particular banquet, Megan said, "I ate before so it was all good," though when she described the previous year's semiformal dance, Megan's perspective was different. She explained that she "didn't really want to go" because there was a "whole meal plan" already made and she "didn't want to bring [her] own food" and have the "chefs come out and be like 'oh here's your food, your special food'" because that would make her feel "awkward" in front of "everybody." Megan was not sure that she would attend this year's semiformal dance.

From Grant's perspective, eating "outside the home is the hardest part" of having food allergies for Megan and noted it is even more difficult when he or Diane is "not with her" as support. Kim concurred and spoke about the semiformal dance and the prom as two schoolrelated social events where she did call the school to inquire as to the meal arrangements. Kim reported that the principal did say "in this awful principal mode [voice] 'thank you for thinking of this" which I inferred from Kim's own tone of voice and facial expression that she was less than impressed by the response she received from the administrator. In both instances, Kim ended up calling each venue to discuss possible food accommodations for her son.

Communicating Food Policies

During participant interviews, I heard various iterations of the "nut-free" school terminology. Other terms participants used included "peanut-free," "peanut-aware," "nut-safe," and "allergen-controlled." Linguistic precision seems very important in communicating to school communities the messaging around food bans and restrictions. Angela explained:

We can't declare the building nut-free because we'd have to be policing each lunch bag that comes in. We'd have to be washing each kid's face as they come in if they had toast with peanut butter in the morning. So it's nut-safe, but we can't guarantee anybody that it's nut-free, and I think that's realistic.

Even with the food restrictions in place, some parents do not understand or refuse to comply with the policies, believing their rights or their child's rights are being infringed upon. Angela shared that at her school they had two sisters arrive at school with peanut butter sandwiches in their lunches. When a teacher called home to remind the parents of the restriction and to explain why
the two girls were "eating in a different room" from their peers, the mother said "oh that's my husband, he doesn't like being told what to send or not send to school. He does that on purpose." During the interview, Angela remarked she "just couldn't believe the lack of compassion" and continued as if speaking to the girls' parents: "For you it's an inconvenience, for somebody else, it's life and death . . . you have no idea what it's like when that kid is laying on the floor." I sensed Angela's frustration, and perhaps anger, with the parents who purposefully chose to ignore the rule, thereby putting other children at risk. As a parent, Angela appreciates that food policies can be "annoying" and shared that for years she could not pack anything with citrus, including many types of fruit juice, fruit cups, or those "beautiful little mandarin oranges" since a child at the school had a severe citrus allergy. Putting the situation in perspective, however, Angela said, "thank God that wasn't my kid." Similarly, I sensed that Kim had also experienced lack of understanding at some point in the past. She shared her typical response:

One of my things I've always said to all those parents who complain that they can't send their kid to school with a peanut butter sandwich, "I'll trade you. I'll trade you any day." I would so much rather be the parent who can't send the peanut butter sandwich to school as opposed to the parent who can't have it in their house.

Kim's comment suggests that a communication barrier might exist around understanding the complexity of individual risk and that more education is required.

WOWBUTTER controversy. When bans on peanut- and nut-containing products have been introduced in schools, many people have used peanut butter substitutes in their children's school lunches. One such peanut butter alternative is WOWBUTTER, a toasted soy spread, manufactured in Ontario. Angela explained that students at her school used to bring WOWBUTTER sandwiches in to school: You cannot tell the difference—it looks like it, it tastes like it, it smells like it. It's really good! So it was a good alternative, but now they said it's such a good alternative, we can't tell the difference so it's now not allowed. . . . So it's kind of a shame in one way because it was such a good alternative. But at the same time, I can see where, yeah, I can't tell the difference; even if I took a bite out of it I wouldn't be able to tell the difference.

Angela acknowledged that the WOWBUTTER restriction is "a disappointment for a lot of people who were enjoying it and counting on it as a safe alternative . . . but it has those drawbacks." Similarly, Carolyn's board restricted the use of WOWBUTTER in its elementary schools, and at her school they had parents "downright refusing" to comply with the policy to the point where the superintendent of schools had to become involved. Parents opposed to the restriction argued that their child "will only eat peanut butter, so WOWBUTTER mimics peanut butter and I need my child to eat at school, so my child's only going to eat this." Carolyn did say that school administration did "a lot of research" before meeting with the parents who insisted on sending WOWBUTTER in their children's lunches. Carolyn explained that the parents who sent the soy product questioned why their children were being isolated at school and suggested that the child with the allergies should be "isolated" instead. Carolyn shared, "I think unless you have a child who has experienced this, it's hard for you to imagine that it is life-threatening." She said eventually the superintendent had to write a letter to the school community explaining the decision and now the reminder goes in every school newsletter.

No food for sharing policy. Perhaps one of the most talked-about issues in parent and teacher interviews was around outside food items being brought into schools to be shared as part of special occasion celebrations. There seems to be a pervasive belief in elementary school

communities that parents should be allowed to supply food treat items for holidays or birthdays—the most popular food-sharing item being birthday cupcakes. Food waste, dietary restrictions or preferences, as well as life-threatening food allergies have resulted in many schools adopting policies to address the concern. Some schools have restricted all outside food for sharing while others do allow teachers to bring in lesson-specific food items that can be used in controlled settings and monitored by the teachers.

Kim, Angela, and Tina talked about how school policies and food sharing practices in schools have changed over time. Kim remarked, "It's not like when we were kids [with] 'I'll trade you, you know this for that'" exchanges occurring during the lunch hour. Angela remembered that when she was in school there was another student who had a nut allergy who did not seem to be included in any activities other than classroom learning:

I know when I was in school there was a boy with a peanut allergy and he had to take a taxi to school and he had to eat in a different room; he was totally excluded for any of those social times. Like he'd be in class with us but never in the lunchroom and he was never on the bus . . . it was almost like he was a freak or something. It was for his own safety, but things are certainly different now.

Tina's experience echoed what Kim and Angela had shared. Tina noted that early in her teaching career there really were no food policies in place and students with food allergies "basically had to cope on their own," whereas now food allergy awareness is prioritized more so than it was in the past. Further, Kim noticed that since her children have left elementary school, "things are less food-oriented" and there are "no more rewards of food," which pleased her.

As an elementary school educator, Angela appreciates the current food policy that does not permit food sharing in her school. She noted that in addition to the many parents who did not want their children eating what other families sent in to school, there was a significant amount of food waste. She shared:

So, I've actually enjoyed having a no food policy because the cupcake brigade coming in for Valentine's day, Halloween, Christmas—it was too much! Or even birthdays when we still did have food coming in, one mom asked if she could send in cupcakes, I said yes but just little ones. You know, they're kindergartens; they're so little, they can't eat much. Oh my gosh she brought in Costco cupcakes. They were huge! They were like mini-cakes and so much of it went in the garbage. Like kids basically licked the icing off or took two bites. If she could have seen how much went in the garbage, she would have been horrified, and of course they have no idea of knowing because they just drop these things off in the morning.

Angela noted that teachers and parents did not really want kids eating "6 or 8 cupcakes during the school . . . day so it was kind of just being wasted. And when you've got a kid in the class with a food allergy they can't have any of that." She admitted some staff members were "leery" about the no outside food policy because they have at times used food in lessons. Angela's principal decided that if food was required for a lesson, school funds would be provided to purchase food that could then be prepared at school to reduce cross-contamination risks. Teachers were not the only ones concerned. Some parents strongly opposed the "no outside food" policy implemented at the school. Angela recalled one parent saying, "you're denying my kid the ability to celebrate their birthday" and she explained that they could still celebrate, just not with food. To express his displeasure with the no sharing policy, a father who attended a school council meeting at Angela's school "walked in with a big bag of like Halloween-type candy and he literally threw it across the table and says 'here's my treats for tonight, help

yourself." Angela remembers being "shocked" that he opposed the food policy, not only because he was employed in the health care field but also because his own children had food allergies.

Barb said she has noticed a difference in school food policies in the last 3 years. At Robyn's school, students are not permitted to bring birthday or holiday treats, but when she first started school, it happened often. When the teachers knew in advance they would let Barb know and she would be sure to send something that Robyn could eat (see *Mom's the word*), but when it "happened without any notice . . . [Robyn] always felt pretty sorry for herself on those days." For Barb, she feels the food policies have "been really great" and have "taken the edge off."

Communicating After an Anaphylactic Event

In her role as vice-principal, Carolyn spoke about how important communication was following an anaphylactic emergency. She recalled an incident at her school where a grade 8 girl had an allergic reaction to a cookie that contained her offending allergen, nuts. Although the girl's friend stated there were no nuts in the homemade cookie, that was not the case, and an educational assistant at the school had to administer life-saving epinephrine to the girl. Carolyn shared that she accompanied the "distraught" student to the hospital in the ambulance where they met the girl's "very grateful" parents. Carolyn admitted that there were a "lot of people in shock" as a result of the incident, including the student who had the reaction and the educational assistant who administered the EpiPen®. She indicated that the experience became an opportunity to discuss food policies and procedures. Carolyn spoke of trust and said that she had to remind the child with the allergies "to not accept anything" from anyone, even when you want to "take the word of a friend." She explained that the "whole situation sort of brought everyone back to … this is serious and we have to go back to our policy and it has to be nut-free food."

Carolyn admitted that firm reinforcement of the school's food restrictions did cause "controversy," as some parents did not want to "abide" by the rules (see aforementioned *WOWBUTTER Controversy*).

Open Communication: Teens and Parents

It seemed apparent to me that the teen participants in my study try to maintain open and honest lines of communication with their parents. Ashley explained that she "plans ahead" and "usually [doesn't] go anywhere that [she's] not familiar with." As well, Ashley says she always has her cell phone on her and tells her parents where she is going. Similarly, Grant said that communication is "one of the keys" and that it is important to be in communication with "whoever [Megan] is with" and know "wherever she's going." Below, I share select details of some of the conversations that teens and parents have had around social relations and situations.

The kissing conversation. As children with food allergies approach the teenage years, there are more things that parents begin to worry about—and kissing is just one such concern. Grant admitted that he doesn't like to think of Megan "growing up and kissing a boy" but cannot help but wonder what would happen if said individual "ate peanut butter" before kissing Megan. Although Megan "squirmed" during the first kiss conversation with her mom, Diane insisted that Megan be "aware of what this boy has eaten because it's going to be a contact thing" and it will not be "pretty" if she happens to have a reaction. Ashley talked about the importance of being "upfront and honest" with the person you are involved with. She stated that she is "still nervous" because it must be hard for someone to "all of a sudden just cut out" the food item that she is allergic to. Angela shared that her daughter dated someone in high school who had a peanut allergy and was always very careful about the foods she consumed. The request for a peanut

butter sandwich clued Angela in to the fact that her daughter and the boy had broken up. Neither Barb nor Kim spoke of having the kissing conversation with their respective children.

Parties and alcohol. Ashley admitted that peer pressure to consume alcohol is a "big" reality for teens. She talked about the importance of being aware and being prepared, noting that label reading would be key—especially regarding "flavourings" that might be listed as ingredients. Likewise, Kim noted that socializing with peers can be hard for teens who have food allergies and it's an "extra little worry" for parents as well. She shared that she has had conversations with her son, in the past, about going to parties with friends and being careful about different types of alcohol that he should avoid. Although she didn't "think it would come down to that," she also reminded him about careful food consumption at parties, indicating that she doesn't want to hear "I didn't know I was eating that handful of peanuts."

Diane and Grant have taken a proactive approach and have already talked to Megan about parties. They know someday Megan will want "to participate and be a part of" social events but worry about what she's "going to do when there's alcohol involved." Grant shared:

It's going to happen . . . but when you have food allergies, certain drinks are going to contain something she's allergic to and then once you mix that with alcohol, people's judgment goes out the window. Everybody can attest to that.

He admitted that they "don't know how to deal with that other than . . . talk[ing] to her about it." Grant said that he doesn't "want to condone drinking alcohol underage" and they "preach as parents 'yeah you shouldn't be drinking, but if you are, you better know what you're drinking and you better make sure you're not allergic to it." Diane stated, "it's got to be strategies, it's got to be scenarios" and talked about advice they have given Megan. She shared: You can't put your drink down and you can't have a person have a swig of your drink
What if that kid had peanut butter toast before they came to the party and took a drink. It doesn't even have to be alcohol, it could be your pop, and now you've got peanut butter oil on that mouth and you're ... having a drink of that, you're going to react.
It seems the peer pressure teens with food allergies face around attending parties and/or consuming alcohol, requires that the teens and their parents communicate openly and honestly *before* such opportunities present. Trust was identified by teens and parents as central to this transition to adulthood conversation. Interestingly, neither Barb nor Robyn discussed parties or alcohol, which might suggest that at 12 years old, Robyn has not experienced this pressure.

A future conversation: Postsecondary school. As one might expect, food allergies do factor into choices that individuals make about postsecondary educational opportunities. The uncertainty about the college or university experience as a whole and whether or not colleges and universities address allergy needs was a topic of conversation in both the teen and parent interviews. The details regarding how safe-care strategies might be applied in a new *away from home* context is something that is concerning for high school students Megan and Ashley. Megan shared that she didn't "really know much about university" but thought that living on campus "with other people" would be ideal—though she was unsure if the university would be able to "accommodate" her food needs. Ashley expressed that "on top of the stress" of her food allergies, she felt that establishing "study habits" and "time management" skills would be that much harder if she were to attend a postsecondary institution away from home. When asked what she might do if she had to move away to attend a particular program that was not offered locally, she laughed and said, "I'd put you in my suitcase and I'd bring you along. All jokes aside Mom, I don't know" admitting that she is "scared to be on [her] own."

Diane thinks 17 is a very young age for any teen to move away "let alone a 17-year-old that has food allergies and can't just eat anywhere." She stated that this would be a "huge, huge challenge" for Megan and, though she is only in grade 10, Diane has already "bribe[d]" Megan offering to "buy [her] a car . . . [so] she can live at home," reminding her that "food would not be an issue." Diane acknowledged that at some point Megan may have to move away to attend a program of choice but shared her hope that Megan can remain at home for at least a "year or two," adding with a chuckle that Megan could "mature a bit more and . . . mommy can get over it." Speaking seriously, Diane did say that if the program Megan was interested in was not offered locally, Diane would be right alongside Megan touring campuses and "speak[ing] to food management." Ultimately, Diane shared they would likely "have to get [Megan] her own apartment so she [could] do her own cooking," remarking that residence "would not be an option" because she "wouldn't trust the meal plan." Grant revealed he "truly think[s] that [Megan] will want to stay home" to attend postsecondary school because she is a "homebody."

Kim thought that her son's food allergies "definitely" played into his selection of a postsecondary institution close to home. She recalled researching different universities and noted that at least one offered an option for students where they could, with a day's notice, order an allergy-safe meal. About residence, Kim remembered wondering how "accommodating" individuals and institutions would be. She shared a comment and question that she asked her son, that any parent in a similar situation might ask: "It's great for you to live with five other guys, but is that feasible with your allergy?"

My personal aside: A parent and educator perspective. With less than a year and a half remaining in her high school career, Ashley is already thinking about her postsecondary school education options. As a parent and educator, I am noticing that her conversations are different

from other students her age. Whereas many students in grades 11 or 12 are talking about the financial aspects associated with the attainment of higher education, my daughter wonders if: (a) her chosen institution will be able to offer her on-campus housing without a mandatory meal plan, or (b) if she will be able to *trust* that a potential roommate will understand her allergies.

In Contact: The Cell Phone as Security

All three girls in my study have their own cell phones and recognized the technology provides an added layer of security as they go about their daily lives. Not only do their cell phones allow the girls to stay connected to their family and/or friend support systems but it also offers fairly reliable access to medical assistance in the event of an emergency. Ashley shared that she "always" has her cell "phone charged" and does not go anywhere without it, her EpiPens®, or Benadryl®. At the time of her interview, Robyn had only had her cell phone for "about a month and a half," but Barb shared that it did provide Robyn with some supported independence as sometimes Barb will get text messages from Robyn regarding her allergies. Barb noted she always has her own phone with her as she "might get an email from teachers with a question about something related to allergies—anything from Ukrainian egg painting to play dough, depending on which stage [Robyn] is at." Although I did not ask which brand of cell phone each girl carried, it is worth noting many cell phones have an emergency medical information feature on the home screen that is accessible without a passcode. If the emergency information is completed, first responders or medical professionals can access potentially lifesaving information, similar to the information currently found on medical identification jewellry.

Summary of Communicating Allergy

In this fourth communication theme, I illuminated the lived experiences and communication practices of the participants in my study. I began by sharing how effective

communication is essential to promote awareness and understanding of food allergies and anaphylaxis—specifically as it pertains to ongoing advocacy. When communication breakdowns occur, not only can individuals with food allergies be put at risk of physical harm, but the emotions of those involved, can escalate. Next, I explored the communication tools and strategies that families and schools employ to ensure the safety and care of children with lifethreatening food-induced allergies in schools. Actual communication practices utilized during the school day and during school-related activities highlighted inclusion as a priority, though not always the result. I then showed how sharing food polices or restrictions with members of the school community can be especially challenging for school leaders, as competing priorities and value systems must be considered. In the next section, I turned back to the family to discuss some of the difficult allergy-related conversations that parents and children in my study have had. I closed the theme with a brief look at the cell phone as a communication tool of choice. *"The most important thing in communication is hearing what isn't said" (Drucker, n.d.)*.

Dis/connect: Ethical Leadership and Decision-Making

As I engaged in interview conversations with my study participants, I began to uncover what I now call *ethical disconnects* between and among the teen, parent, teacher, and school administrator participants' perspectives. Three types of disconnects resonated with me and I share them in my final theme: (a) the implementation of policy into practice; (b) allergy and anaphylaxis training, and (c) trust and compliance with school policies and/or procedures.

The Implementation of Policy into Practice

All Ontario schools are required to adhere to *Sabrina's Law* with respect to the care of students with life-threatening allergies and anaphylaxis in schools. Board and school-based policies and procedures, however, are not consistently applied within or across boards of

education in Ontario and seem to depend on the students with life-threatening allergies who attend each individual institution. Schools mentioned by the participants in my study appear to operate on a *best interests* of the individual student model. As previously detailed in *Communicating Allergy*, parents reported meeting with school administration and teachers to discuss their children's specific allergy needs and develop individualized plans. As an elementary teacher, Angela expressed frustration with some aspects of the individual model, indicating that lack of consistency has made it more difficult for school staff to ensure the safety of children both with and without food allergies. She noted the example of epinephrine storage and said that while she knows most of the 500 students in her school and knows who carries an auto-injector, it does not necessarily mean that she knows where a child's EpiPen® is at any given moment. She stressed the office is too far and students with life-threatening allergies need to be carrying their devices on them. Angela reported, however, that access to an EpiPen® proved problematic for a 4-year-old student at her school who was accidentally jabbed in the finger by his friend's EpiPen® during an impromptu lesson the 4-year-old friend was delivering on auto-injector use.

A problem with individual interpretation. In Angela's view, the implementation of policy without clear communication of expectations can lead to the inequitable application of rules. She shared a recent example of a primary student at her school who brought a peanut butter sandwich to school and Angela's teaching colleague "threw it out and told them they couldn't eat it." Angela wondered if that really was the case, that the child could not eat the sandwich. She said, "I don't know that that was the right way to handle that ... I don't think you can deny a kid their lunch just 'cause they've got some other food in there too." Angela felt that clear direction from the school administrator would have been helpful in that instance.

Policies and students: Who knows? While all four parents felt confident they knew their respective elementary school's food allergy policies, not one of the parents could articulate the food allergy policies at their child's secondary schools. This appeared to me to be especially challenging for parent participants in my study whose children attended a grade 7 to 12 school because it seemed that the rules were different in the elementary areas of the building than in the secondary spaces. Not one of the three parents whose child is currently enrolled in a secondary school program discussed having a meeting with the secondary administrators or teachers before the start of the school year. Diane cited the small community school as the primary reason for not facilitating a meeting with or sending a letter to secondary school personnel—feeling like the teachers already knew her child. Diane also stated her daughter didn't "want [Diane] to go in with [her] guns blaring." Interestingly, Megan, whose parents were convinced that the teachers knew about the girl's allergy, said in her interview, "I don't even think the teachers even know that I have allergies, to be honest . . . they don't know, but the office knows and the principals, the teachers don't know." Megan thought that having a meeting with the administrators and teachers might be a good way to ensure everyone is trained in case of emergency—something that parents of secondary school students tend not to facilitate as often as they do with elementary teachers. About Megan, Diane stated, "she's 15 years old. If she has issues, she has to learn to bring them up in a proper manner to the appropriate people" which seemed to suggest that some transfer of responsibility for safe-care at school had begun.

"From grade 8 to 9 it's like a totally different world." Kim articulated that "high school is not the same as elementary school" with regards to peanuts and noted that "you can bring a peanut butter sandwich to high school." Similarly, when asked if her teachers enforce food policies at her high school, Megan paused and said, "I don't know." In her experience as a

secondary school educator, Tina stated that "high schools, generally, they don't have that [no nuts] policy." She continued:

You're aware of it and they'll say no food in the classrooms and they'll be diligent, but there's nothing stopping students from bringing any peanut products or other products that people are allergic to.

By the time students reach high school, Tina said, "it's kind of been trained into them" from the elementary school teachers, and many students do not bring products containing nuts to school.

Tina acknowledged the lack of allergen "policing" in secondary schools and said that "if you're a student who does have a severe allergy, then it's definitely a lot trickier in that environment to stay away from people with whatever product that it is that you're allergic to." The teens in my study concurred—Megan and Ashley both talked about avoiding their respective schools' cafeterias where the likelihood of encountering allergens is quite high, despite their schools' claim to be "nut safe." Megan said, "Since our school isn't peanut free (you're allowed to have peanuts in there), I don't really go to the cafe." Ashley commented that she tried to avoid busy hallways during the noon break and tends to "sneak" her own lunch at her locker.

As an elementary educator, Angela voiced the disconnect when she commented that the "loose" allergen policy in high schools "seems like it is a total shift in thinking." She noted that "it's not like when you turn 13 or 14, you're suddenly not allergic to those things anymore." Angela shared her concerns:

That's one thing I really wonder about because we're so careful in grade school . . . about policing this and it's like grade 9 all bets are off. It's like you can take whatever you want, you can eat whatever you want, wherever It's assumed that all of a

sudden, that they're 13, they're immune to it? You know you're a big kid now, you're going to take care of yourself. It just seems like nobody cares after grade 8.

As an educator and also a parent, Angela said that enforcement of food restrictions in secondary schools is "not happening." Angela supported her comment by saying that she "[doesn't] recall ever getting anything home from the high school saying 'just a reminder we're a nut-safe school," though she is aware of her board's policy.

Allergy and Anaphylaxis Training

The educators in my study shared varying perspectives on the anaphylaxis training they receive in their schools. Although researchers strongly suggest regular allergy training opportunities occur every 4 to 6 months (Russell & Huber, 2013), Angela, Tina, and Carolyn all said that anaphylaxis training in their respective schools occurs *only* early in the school year and most often at the September teacher meeting. Tina thinks that the training is "really for new people" and is "just a refresher" for her and others who have "seen it a number of times." She said that the training itself is typically done by the principal or vice-principal of the school and consists of the "clip off, jab, and you're done" EpiPen® demonstration. She shared that the administrators also "highlight . . . at some point" the kids who have allergies.

Regarding anaphylaxis awareness training, Angela remarked that this is often the part of the staff meeting that is "not taken seriously" and where "people say 'ugghhh, I've had that training before' [and] roll their eyes." Despite having children at her school with life-threatening allergies and anaphylaxis, Angela could not recall any recent training having been offered at her school—reflecting that an administrator change 3 years ago might explain the absence of training. Angela did share however that, in the past, allergy and anaphylaxis training has included an auto-injector demonstration, followed by an opportunity for staff members to try the

training device. She said that sometimes the training makes mention of the signs and symptoms of anaphylaxis and sometimes it does not.

Carolyn's report of the anaphylaxis training that occurs at the September staff meeting mirrors both Tina's and Angela's comments. She said that as an administrator "you have your procedures and your staff meeting items that you have to make sure that everyone completes" and anaphylaxis training is one such item. Carolyn also stated that "when you're a vice-principal . . . you have to follow the lead from your principal" and although you "can offer it up as much as you can," ultimately "the principal [makes] the decision on what the agenda looks like for the staff meeting." Interestingly, Carolyn said that she received no formal training around anaphylaxis either from her board or during her Principal's Qualification Program (with the exception of a small independent project she initiated herself). Further, Carolyn suggested there are many things that "have to be practiced more often than just the first staff meeting in September" and named concussion and asthma awareness as two examples. She explained that teachers have "so much information that is thrown at them" at the first meeting that "it is hard to remember because it's information overload." Carolyn thought that "a little reminder at every staff meeting, in different ways" would help.

Do nonteaching staff members have any training? To the best of Angela's knowledge, she was not aware of any secretarial, cleaning, or support staff ever taking part in food allergy or anaphylaxis training sessions, which she perceived as a gap in supporting individuals with allergies in schools. As an administrator, Carolyn was also not aware of any special training that the custodian or the cleaning staff might have had around allergies and anaphylaxis because "they're in a different union," "their meetings . . . are at a different time than the teachers'," and they "don't come to the [school] staff meeting." Carolyn did note that in their roles, cleaning

staff would "have a list of which classrooms they would have to clean" and would know which classrooms had children in them "who had allergies," but there is no formal procedure or policy. Upon reflection during the interview, Carolyn remarked:

I should have taken it upon myself to ensure that he was aware because the custodian is an extra pair of hands, set of eyes in the building and should know how to use the EpiPen® and should know where they are.

Carolyn's comment calls to mind Angela's admission that she is "probably not as vigilant" about allergies when she doesn't have a child in her class who has food allergies; yet it was Angela who came upon a student experiencing an anaphylactic reaction and had to administer epinephrine. Angela's example illuminates a gap in practice and reinforces the need for *all* adults in schools to have an understanding of allergies and anaphylaxis. Likewise all adults in schools (not just educators) need to trust that their staff members and contract colleagues will know what to do in an anaphylactic emergency.

"There's not a lot of supervision at lunch." Carolyn, Angela, and Barb all talked about the lack of adult supervision in elementary schools over the daily lunch breaks—ironically, the riskiest time of the school day for students with food allergies. All three women discussed what seems to be an increasingly common practice of hiring contract lunch supervisors in combination with grade 7 and 8 student lunch monitors. Carolyn shared that her elementary school hired two adult supervisors to monitor a student population of over 500 students during the nutrition breaks. She stated that each supervisor was responsible for monitoring six to eight classes of students at one time but noted that she was not aware of the exact training, if any, that was provided to them upon hire.

Angela admitted that the most challenging aspect of her job is that she is "not in the room with [her] kids at lunch time" and, as a result, "there's not a lot of supervision." As well, she shared that her designated preparation time is scheduled right before lunch and she is "not there when [her] kids are getting out their lunches." As a primary division teacher, Angela said that she would normally ask her students if anyone has "anything [that] has nuts in it . . . just to get them thinking about it and [she] would go around and look." Angela stated that now that she is not in her classroom, she is "trusting that the parents have done the right thing because [she] know[s] the lunch lady is not checking." Angela stressed that "none of the teachers are in the classroom with their own kids at lunchtime" and that there's really only "one adult between several rooms." She remarked that the lack of supervision is not concerning only for students with allergies "but for choking or anything," noting that school leaders are "counting on a grade 6 student, who's probably . . . not really paying much attention, to be the adult in the room." When I inquired as to whether or not Angela had ever asked her principal to rearrange teacher preparation times to increase adult presence during lunch, she replied that she had for another reason and was told "it's a really, really complex thing ... and it's such a domino effect" so is reluctant to ask again.

As a parent, Barb found it a "hard step" to see Robyn transitioning from "having a lunch buddy [in grade 5] to being a lunch monitor" in her grade 6 year because one adult supervisor with responsibilities for five classrooms was "just not enough." In order to have Robyn act as a lunch monitor herself, she required the support of another peer buddy who "knew what to look for" in terms of her allergies. Barb said the plan worked except when Robyn's own buddy didn't show up, she would have to tell her teachers she could not monitor alone because the younger children in her care would not necessarily know what to do in an emergency. Carolyn feels that the grade 7 and 8 lunch monitors in her school could have benefitted from more specific training on the "important things like what to do when there's something happening to a child," knowing how to "pick up the phone that connects right to the office," or using the phone to say "this is an emergency, I need help." She continued:

So when I have that first meeting with them, it's not about what the kids do when they're done their lunch or how you help them get dressed—I think it's more important things: what if someone's choking, what if someone has an allergic reaction.

Carolyn also thought that explicit strategy training could be appropriate for the student monitors. She thought things like "run[ning] to the staff room, find[ing] the lunch room supervisor, [and] ask[ing] your friend who's in the classroom next door" would be realistic for student monitors.

Perceptions of Trust and Compliance

In order to ensure the safe care of individuals with life-threatening food allergies and anaphylaxis in schools, families rely on all members of the school community to comply with protective policies and procedures. Angela seemed to capture the essence of the disconnect between the theoretical ideal and the reality of practice when she said:

They put a lot of trust in the world—when that kid walks out of their sight, they're trusting everybody that that kid comes into contact with, to do the right thing, and sadly, that's not the way it is.

In the subsections below, I highlight select troubling ethical issues around compliance as pertaining to food allergy and anaphylaxis policies in schools.

"Principles, unless you're going to get paid otherwise?" Carolyn, Tina, Angela, and Barb all spoke of their respective schools hosting food-related fundraisers. At Carolyn's school, pizza and pasta lunches are offered for weekly purchase. Families can preorder for a specified time period, and a portion of the total sales are returned to the school. Carolyn did not mention any students at her school who have allergies to the ingredients in these two menu options.

While long-term fundraising strategies seem popular in elementary schools, the shorter term campaigns tend to generate more interest in secondary schools. Tina shared that her school does sell chocolate-covered almonds because they are a "popular seller" despite having students in her school with nut allergies. Similarly, Angela commented that at her own child's high school, one-day fundraisers such as group bake sales or special event concessions are popular. Angela shared "there's never [been] any concern about any nuts . . . and [her] kitchen's not nut free." She said it seems like "it is not important anymore" once the students reach high school.

At the school where Angela teaches, premade cookie dough is sold as a fundraiser. Angela explained that orders are filled through a catalogue and, when the product is delivered, the parents are required to go to the school to pick up their orders. Angela stressed that the "containers are sealed" and that "children are not allowed to take it home on the bus because there is cookie dough with nuts and peanuts in it." Angela did note that school administration was questioned about the cookie dough sales but felt their established pick-up policy "should be safe because it's all adults" who are organizing and transporting the cookie dough.

Barb offers a different perspective on cookie dough fundraisers in elementary schools and shared her parent experience during her interview. Barb was troubled that "peanut butter cookies [were being sold] out of the gym" at Robyn's former school. She shared that while Robyn "doesn't have an airborne nut allergy . . . other kids do [and] teachers do." When Barb spoke with school administration she recalled saying "do you realize that you're teaching your kids that's great to have principles unless you're going to get paid otherwise?" She admitted they "weren't receptive" to her feedback and was told "but this is a really good fundraiser for us."

Barb stated that she suggested that the school find a "manufacturer who sells nut-free products" and, while the school did stop selling peanut butter cookies, they continued to sell macadamia nut cookies. The whole situation made Barb "so livid that this is what they were teaching the kids" that she called out administration on their actions:

You're serving up these products that may contain nuts, in your gym, during an assembly, and then you're telling the kids "oh by the way, you can't bring those to school"—you're selling a product that you know they're going to put in their lunches, and you know they're not supposed to bring it to school because it may contain nuts. When Barb questioned the ethical decision-making of the school administrators, they appeased her by allowing Barb to draft a letter to be sent home "reminding people that they weren't

supposed to bring [the cookies] in" to the school. On principle, Barb "boycotted" the fundraiser.

Intentional disregard of the rules. Perhaps the most alarming ethical disconnect I uncovered during participant interviews centred around school staff members giving food treats to students with food allergies. Barb shared that one of Robyn's elementary school teachers had a "very bad habit of treating kids with candy" and seemed to not understand the simple rule that Robyn had to follow to stay safe and alive—"if it doesn't come from home, or it's not preapproved, she doesn't eat it." On three separate occasions this particular teacher gave Robyn jelly beans, jujubes, and licorice, and when Robyn told her teacher that she could not have the treats, the teacher would say to Robyn "oh yes you can, I've looked at the ingredients, you're good to go." During the interview, Barb pointed out that this series of incidents occurred before Canadian labelling laws changed to require food manufacturers to say "this contains milk" instead of saying "sodium caseinate," so Barb felt that there was no way that the teacher knew the "47 different names that milk goes by." Barb recalled that when Robyn came home she was

"very confused" and wondered if Barb had in fact talked to the teacher and had forgotten to inform Robyn. After the first incident, Barb called the school and said to the teacher:

We have a rule to keep [Robyn] safe and you're just confusing her . . . and as a teacher she wants to please you and you're putting her in a really bad place; she came home really confused. Don't do that again.

Unfortunately the same teacher gave Robyn treats two more times that school year and, after the third instance, during a third phone call, Barb told the teacher that Robyn would be removed from the class if it happened a fourth time. Barb said the teacher was "shocked" by the idea of Robyn being taken out of the class over the issue and explained that she "didn't want to give [Robyn] something that the other kids aren't having," to which Barb replied, "she does it all the time and she would be far happier if you would just stick to her own treats."

Teachers were not the only board employees to give students with food allergies treats or snacks. Robyn also had an educational assistant give her peanut M&M'S® as a thank you treat for her help when she was a grade 6 lunch monitor. When Robyn told the educational assistant that she could not have the candy, she told Robyn to "give them to her brother" and sent Robyn home on the bus with the treat. In her interview, Barb seemed frustrated that the educational assistant even had a peanut product "on school property, let alone giving it to a kid she knows has allergies." Barb was grateful that Robyn was "smart enough" to acknowledge and say "this was dumb." Kim shared that once the school's lunch supervisor had called her at home to tell Kim that she had given out candy and, while she thought that they were nut-free, in fact the label said "may contain traces of nuts." Kim pointed out that while the supervisor did drive back to the school to check her son, Kim "[doesn't] like the idea of somebody telling [her] child that this is nut-free" because everyone has a different interpretation of what "nut-free" means.

"**Contraband.**" From her teacher perspective, Angela commented that it is not just parents who unknowingly or intentionally disregard the school's nut control policy. She shared:

Teachers don't always practice what they preach. So we're really tough on the kids, and then you walk in the staff room and it's all in there. It's almost like if you're sneaky about it, you're okay. If you have chocolate-covered almonds and nobody sees them, you're fine. Or as long as that supply teacher who you know has food allergies is not supplying at your school that day, you're okay, you can have those chocolate-covered almonds.

She remarked that some staff members even use the code word "contraband" when inquiring if anyone has any allergen-containing foods in their lunches, which she said indicated is proof her colleagues know what they are doing is wrong.

Ashley shared that when she walks by the staff room at her school, she can "smell" when someone has something in their lunch that contains nuts. She said, "they just think, cause they have their own little room, it's contained, but it's not." She also commented that "the worst is when a teacher who you have a good student-teacher relationship with consumes your allergen and betrays your trust—it's hard to look at that person the same way." She described this loss of trust as a step back in their relationship that has a serious negative effect on her learning in that teacher's class because now, in addition to trying to learn, she worries whether she is at risk while under that teacher's care. She stated the relationship is "really awkward, 'cause we both know that it happened but we both don't address it," and though she "sometimes" wants to talk to the teacher, she feels "it's better not to cause a scene." Ashley holds her teachers to a higher ethical standard and expects them to model rule-following behaviours while at school but wonders if they "just [get] better at hiding it." When students are away... is it okay? Angela recounted a board-wide professional development day that was being held at her school where the superintendent of schools brought in muffins. Angela took what she thought was a bran muffin, only to bite into it and realize it was a carrot-nut muffin:

I looked and I realized there were nuts in this muffin and I just about died! I was shocked that the superintendent had brought these in, and then I was horrified that I was sitting beside this lady who I knew was severely allergic who has had to leave school before because somebody in the staff room had a nut product in their lunch.

Angela explained that she immediately left the room and tightly wrapped the muffin up and put in the garbage before washing her hands and face, and rinsing her mouth. She also let the woman with the nut allergy know what had happened. When Angela told the organizers that some of the muffins contained nuts, the superintendent replied, "yeah but the kids aren't here today." Angela admits being "shocked" because she had "trusted" that the leaders would be sure to make the simple request as a precautionary measure and order muffins without nuts. Angela stated, "these are people who should know better. I can see the parent at home not realizing, because they're not in the business, but when you're in the business . . ."

My personal aside. At times during my research study I noticed my own emotional response to what participants shared. As a parent and an educator, I admit am deeply disturbed by the teacher who on three occasions tried to give Robyn treats that were not previously approved by Barb. To me, the intentional disregard of the very rule that keeps Robyn safe and *alive* is ethically troubling; as a mother, it is just plain scary to think an educator believes (as evidenced by the three attempts) that there was nothing wrong with giving Robyn the treats. As a parent, educator, and researcher, I feel an overwhelming sense of responsibility to continue to

work to help broaden food allergy and anaphylaxis awareness in educational settings (preschool through to graduate school).

Locked and Loaded: The Cupboard and the Gun

Two disconnects symbolically represent this final theme in my study—alone, each is powerful, but together they evoke a strong sense of symbolic tension that exists around ethical leadership and decision-making in schools.

Storing EpiPens® in a locked cupboard. When Kim was a parent volunteer in her son's elementary school, she had insider knowledge that life-saving epinephrine was being stored in a locked cupboard in the main office. Tina also shared that at her previous school, students' EpiPens® were kept in the school vault and staff did not have access to the autoinjectors if working or supervising extracurricular activities outside of regular office hours. Tina's current school does have an easily accessible EpiPen® in the main office that is not prescribed to a particular student but could be used for anyone who might require the life-saving drug.

When Carolyn arrived at her school as an administrator, she noticed that epinephrine auto-injectors were kept in a "locked cupboard in the office that only the secretaries had access to." She shared that the principal had given secretarial staff the responsibility for the cupboard but, in doing so, had limited the access to it. Questions like "what happens if the child is outside and forgets their [EpiPen®] fanny pack?" or "what if the child is upstairs and the EpiPen® is downstairs in a locked cupboard?" prompted change in the epinephrine access in her school. Carolyn said that any student with life-threatening allergies carries an EpiPen® on her/his person, the student's classroom teacher has an EpiPen® in the teacher desk, and the cupboard (though still locked) is more accessible than it had previously been. The loaded gun. Ashley indicated that some days she feels that going to school is a "metaphorical" game of "Russian roulette." She said:

It's like somebody has a gun . . . and I don't know who the person is, and I don't know when that bullet's coming. I don't know when I'm going to have an allergy attack . . . I don't know who is going to be eating it. I don't know where it's going to be, but I know I always have to be watching and be prepared. It's like somebody having a gun to my head and just clicking away until the *bullet*, or the allergy attack, kills me.

Ashley feels the severity of her nut allergy in combination with the unpredictable behaviours of others makes her vulnerable. For Ashley (and perhaps the other children in my study), there is an ever-present fear that she will experience a life-threatening anaphylactic reaction at school. For me, as an educator and parent of child with food allergies, the image of the loaded gun, juxtaposed alongside the locked cupboard, suggests a troubling disconnect—the persistent fear of threat to one's physical safety coupled with a potentially unnecessary barrier to life-saving care.

Summary of Dis/connect: Ethical Leadership and Decision-Making

By calling attention to the ethical disconnects in my fifth theme, I illuminated policy to practice gaps that exist within schools around food allergy and anaphylaxis. Specifically, I highlighted concerns related to knowledge, understanding, and interpretation of anaphylaxis policies in schools. I then considered the different kinds of training that school staff and students receive in both elementary and secondary schools. I noted issues of trust and compliance by sharing participants' experiences with school decisions that did not seem to be made with the best interests in mind. I closed the thematic discussion by exploring the locked cupboard and the loaded gun as two symbols that seem to me to represent the concept of ethical disconnect.

"The educator-leader has to be responsible for nurturing and sustaining a learning environment characterized by authenticity and responsibility" (Starratt, 2004, p. 55).

Summary of Chapter Four

I began Chapter Four by sharing my data interpretation and analysis strategies. I detailed the within-interview, within-group/cross-participant, and cross-group/cross-participant interview interpretation and analyses procedures. As well, I added a brief section explaining how my life experiences have shaped my worldview and ultimately my personal interpretation of the data. From there I explored my five emergent themes, beginning with the consideration of allergy as both an individual and a shared identity that is constructed and reconstructed by stories. memories, and relationships. My second theme looked at the rules, routines, and safe-care strategies that the participants in my study regularly use to ensure the safety of individuals with life-threatening food allergies and anaphylaxis both in and away from safe home environments. A discussion of labels and labelling followed as my third theme, and I discussed the advantages and disadvantages of label reading, creation, and use. My fourth theme addressed how, and for what purposes, allergy is communicated. I considered personal and school-based communication practices that advocate for the awareness and understanding of food allergy. In the discussion around my fifth theme, I illuminated for the reader select ethical disconnects that participants in my study shared. The disconnects, in my view, shed light on policies, practices, and ethical decision-making processes that require new understandings of food allergy and anaphylaxis in schools in order to improve the physical, social, emotional, and academic experiences for individuals who have life-threatening food allergies and anaphylaxis. I closed each thematic discussion with an image (or images) that in my view exemplified the theme.

CHAPTER FIVE: REVIEW OF MY STUDY; IMPLICATIONS FOR PRACTICE; IMPORTANCE, STRENGTHS, AND LIMITATIONS OF THE STUDY; RECOMMENDATIONS FOR FUTURE RESEARCH; AND MY FINAL THOUGHTS

In this qualitative case study it was my intent to uncover how the school experiences of children/teens with life-threatening food-induced allergies and anaphylaxis are constructed and given meaning (Denzin & Lincoln, 2005). In this, my final chapter, I begin by providing a review of my study as a whole, situating it within the extant literature around food allergy and anaphylaxis in schools. Five themes emerged from my interviews with children, parents, teachers, and an administrator. I now consider how each theme might align with a "best interests" of the individual student model for ethical leadership and decision-making in schools (Shapiro & Stefkovich, 2005). As well, I now reflect on the significance of my three subthemes. Based on the findings of my study and the implications for practice, I offer select ethical calls to action. Next, I outline the importance of my study, noting both strengths and limitations. I close the chapter with my recommendations for future research studies and share a few final thoughts.

Review of the Study From My Perspective as a Mother

During my allergy and anaphylaxis research, I found many studies that afforded me new ways of thinking about the physical, social, emotional, and academic aspects of food allergy. As a mother who has responded to questions from well-meaning individuals who ask *why there are so many allergies these days?* or *can't she just eat a bit?* or the heartbreaking *why do I have food allergies?* question from Ashley, I try to educate myself as best as I can in order to provide informed responses. Each piece of literature I reviewed contributed to my study in some way, though certain pieces continue to resonate with me. Here, I locate my study within the literature in order to address my research questions: What are the school experiences of children with food allergies and how might the illumination of these experiences serve to guide policy and practice?

Piecing Together the Food Allergy Puzzle

As a mother of a child with life-threatening allergies to food, I think I will always be searching for an explanation as to the biological cause(s) of food allergy, as I hold out hope that knowing the cause(s) may lead to a cure. Although Strachan's "hygiene hypothesis" seems to be the most commonly accepted general explanation for allergies, it only really makes sense to me in terms of the "protective" advantage offered to later born children (Strachan 1989, 2000). The hygiene hypothesis does not clearly explain why Ashley, Megan, Robyn, or Kim's son each experience such negative physical reactions to food while their younger siblings do not. Keet et al.'s (2012) study that found that fall- and winter-born babies were more likely to develop food allergies also does not ring true for the three child/teen participants in my study (or Kim's son), whose birth months include May, June, September, and November. Similarly, mode of delivery research by Renz-Polster et al. (2005), which indicates that babies born by caesarean section are more likely to develop any kind of allergy, does not seem to apply to Ashley, Megan, Robyn, or Kim's son, as none of the four experienced a caesarean birth. Although I am not sure if Kim breast-fed her son, all three girls in my study were breast-fed as infants and, in theory, should have had some degree of allergy protection as a result—which may, in fact, be the case (Bergmann, Wahn et al., 1997). Considering the aforementioned studies and criteria, it seems reasonable to posit that Ashley, Megan, Robyn, and Kim's son should not have developed severe food allergies-and yet they did. I often wonder how much worse Ashley's food allergies could have been and similarly wonder if there was something I could have done differently when pregnant or nursing that might have changed the allergy-related health outcomes for my child.

Two studies, those of Kusunoki et al. (2012) and Karmaus et al. (2001), continue to resonate with me and together seem to offer, in part, a plausible explanation for food allergy. To

recap, Kusunoki et al.'s (2012) study found that each successive pregnancy a woman experiences reduces the levels of Immunoglobulin E in her body. When paired with Karmaus et al.'s (2001) study which found a correlation between high levels of Immunoglobulin E in cord blood and atopic disease, this seems to offer a more *immediate* explanation for allergy than the aforementioned hypotheses (see previous paragraph). From an *evolutionary* perspective, Rook et al.'s (2003) "old friends" hypothesis suggesting that rapid urbanization has resulted in a loss of supportive helminths and bacteria continues to intrigue me (Rook et al., 2003; see also Elliott et al., 2007; Velasquez-Manoff, 2012). It was interesting to realize, when learning about Profet's (1991) toxin hypothesis, that it was the first time I had considered allergy and anaphylaxis as positive—albeit in a 'canary in the coal mine' kind of way. I remain curious about the effects of urbanization and wonder if "allergy sufferers [really do] have special powers of perception" (Mitman, 2007, p. ix). Similarly, I continue to contemplate Vaughn's "serum sickness" theory that posits human-made illness can be brought on by injected medicines (Vaughn, 1941).

The specific cause of food allergy continues to challenge researchers, particularly given the absence of pathognomonic symptoms and multiple, varied manifestations of allergy (Cruz et al., 2007; see also Kumar et al., 2005; Larsen et al., 2016; Nettleton et al., 2009). I feel my introductory participant profiles, in combination with my thematic exploration of allergy as an individual identity, showcase for the reader a range of individual physiological responses to offending food allergens and highlights the complexity of allergic disease.

The Safety and Normalcy Balance

Aspects of food allergy were touched on in all five of my themes, although the identity, strategies, and communication themes seemed more robust than the labelling and ethical disconnects themes with respect to daily life. Regarding identity, the child/teen participants in

my study reported that, for them, life with food allergies is just "normal," though they did share some physical, social, and emotional obstacles and challenges to full participation, which is consistent with the normalizing and redefining allergy literature offered by Fenton et al. (2011, 2013), Marklund et al. (2007), and Pitchforth et al. (2011). It seems that the management and communication strategies parents use to prevent their children from coming in contact with offending allergens work for the most part (Akeson et al., 2007).

While all three girls knew allergy-related stories from their younger years, the details of those stories were more often provided to me by the parent participants in my study. This is consistent with the work of Akeson et al. (2007) who found that parents could "vividly recall" their child's early allergic reactions though the children could not (p. 1215). That is not to say, however, that the child/teens in my study could not recall ever having a reaction; rather, their early reactions were more likely to be detailed by their parents.

About responsibility. In studies around the maternal and familial experiences of childhood food allergy, Rouf et al. (2011) and Alanne et al. (2014) found that mothers assumed the primary responsibilities for the care of children with food allergies. While the mothers in my study did *not* report an unequal distribution of responsibility as related to the care of their children with food allergies, one might speculate that the three to one, mother to father participant ratio might be representative of responsibility. The mothers spoke openly about their spouses who "grocery shop," "cook," "clean," advocate for their children, and attend appointments. As the only father to participate in my research, Grant did directly state that Diane "carries more of the burden" for medical appointments for all their children, but "especially" for Megan. An examination of the mother–child relationship in the identity theme

saw Robyn label Barb as the "allergy expert," and both Angela and Robyn recognized moms as the parents who approve special treats sent to school.

The participant experiences of allergen avoidance, as detailed in my second theme around responsibility and safe-care strategies, are consistent with those reported in the extant literature. Parental motivation to "avoid recurrence" (Pitchforth et al, 2011, p. 257) was evident in every safe-care strategy that the parents discussed, including: label reading to avoid allergen contact and consumption, substituting ingredients, preparing allergen-free meals, using separate cooking tools, and establishing strict cleaning protocols (Altschul et al., 2001; Herbert & Dahlquist, 2008; Pitchforth et al., 2011). Label reading to avoid coming in contact with hidden allergens, in my view, is worth further mention here, if only to promote awareness. Situated within the three themes of strategies/responsibility, labelling, and communication, Ashley, mothers Barb and Diane, as well as educator Angela spoke of reviewing nonfood item labels on makeup, creams, craft supplies, sunscreen, and "lip chap" to avoid contact with hidden allergens. Although these types of products are mentioned in the extant literature as potential sources of hidden or undeclared food allergens, my sense from participants in my study is that this information is not well known by those outside of food allergy conversations (Food Allergy Canada, 2016; O'Neil et al., 2011; Russell et al., 2012; Russell & Huber, 2013; Weeks, 1996).

Eating food prepared away from home was described by parents and children in my study as both challenging and stressful, a scenario that is also reported by Akeson et al. (2007), Herbert and Dahlquist (2008), and Marklund et al. (2007). Similarly, teens Ashley and Megan articulated they do not like being the centre of attention in situations where they are required to communicate about their allergies. In her interview, Megan, frequently used the term "awkward" to describe such encounters. My study finding is consistent with Marklund et al.'s (2007) work that reported that teens with food allergies do not want to be a bother to others.

Familial well-being. Although emotional well-being was an aspect of the literature I considered, it did not emerge as an independent topic of discussion during participant interviews. Rather, specific situational examples used in context were threaded through participants' interview conversations to provide momentary glimpses into some emotional aspects of daily life of a family dealing with a food allergy. Interestingly, the research around the mental health care needs of families who have children with food allergies has focused primarily on parents (Annunziato et al., 2012; Bartnikas & Phipatanakul, 2015; Herbert et al., 2012; Rouf et al., 2011; Springston et al., 2010; Warren et al., 2015; Williams et al., 2009). Similarly, it was the parents in my study who utilized the words "stress" or "stressful" 19 times to describe how they felt: when sending their children to school (Bollinger et al., 2006), "eating out" at restaurants, or when their children were away from home on school trips. Parents reported "stressing more about social aspects" of their children's daily lives with food allergies than the educational aspects—with the exception of conversations focused on postsecondary school options and opportunities. Three parents spoke of the added stress teens with food allergies might face if they move away from home to attend college or university, an issue which was previously addressed by Akeson et al. (2007).

Only one occurrence (each) of "distress" and "stress" was used by the teens (to describe an allergic reaction and, interestingly, to express concern over moving away to attend postsecondary school). One girl and an unrelated parent participant used the term "anxiety" when sharing their respective feelings about being in, or preparing for, new or unfamiliar social situations. Carolyn used the term "anxiety" to describe her perceptions of student worry about allergies. No participant spoke specifically of having accessed mental health supports because of food allergies which could be in part due to privacy concerns or accessibility barriers such as those addressed in Annunziato et al.'s (2012) mental health care needs and utilization study.

Emotional response. Although Noone et al. (2003) identified death as the number one fear of parents of children with food allergies, the parents in my study did not speak about death; rather, they spoke of *living* by the restrictions of their child's food allergies. Teens' primary concern as reported by Noone et al (2003) was social isolation, which was evident in numerous ways in my study, some of which included: avoiding social situations, bringing own food to social events, or having parents accompany the girls to social activities beyond times that other parents attended.

In their study of the maternal experience of having a child with a food allergy, Rouf et al. (2011) noted mothers experienced "trauma, grief, anxiety, and hope" (p. 54), which I noticed with my study participants' data as well: (a) trauma witnessing an anaphylactic reaction or during the oral food challenge test; (b) grieving the loss of a life *before* food allergies; (c) anxiety around shopping, eating away from home, sending children to school and on school trips; and (d) hope when children are undergoing repeat allergy testing. In a similar way, parental anxiety around "normal" teen behaviours was expressed as a concern by all four parent participants in my study in the communication theme, with specific references to kissing, parties, and postsecondary school.

Safe Care at School

I used Shapiro and Stefkovich's (2005) *best interests of the student* model as a framework for thinking about my participants' stories and experiences of food allergy at school. Two of my five major themes, communication and ethical disconnects, emerged as representative of my study participants' lived school experiences. I originally intended, in this section, to situate my study findings within the four ethics of justice, the profession, critique, and care. As I attempted to do so, however, I found the complexity of participants' experiences were not neatly bound within one ethic; rather, the experiences were multidimensional and required a multiparadigmatic approach (Shapiro & Stefkovich, 2005).

In brief, *Sabrina's Law* requires that all Ontario schools and boards of education create and maintain anaphylaxis plans for individual students, provide regular anaphylaxis training for employees, provide storage for epinephrine auto-injectors, implement allergen reduction strategies, and develop a communication plan for disseminating information about allergies and anaphylaxis to members of the broader school community (*Bill 3*, 2005). In a broad sense, the participants in my study acknowledged that allergy and anaphylaxis policy implementation *is* happening in schools; however the degree to which it is implemented in practice varies greatly. My current 2016 finding is consistent with Behrmann's (2010) report of the inconsistent application of anaphylaxis policy.

Training in schools. With respect to allergy and anaphylaxis training in schools, all three educator participants in my study noted significant gaps around: who receives training, the frequency and quality of the instruction, and the perceived interest in or relevance to the job. While much of the extant literature around allergy and anaphylaxis training recommends *all* school staff members participate (Muñoz-Furlong, 2006), this practice does not appear to occur in the schools where Angela, Tina, or Carolyn work. To clarify, not one of the three women could say with certainty that every adult in their respective schools had participated in anaphylaxis training or had the same quality instructional opportunity provided to them. The two teachers and one vice-principal in my study reported that if *Sabrina's Law* is reviewed in a

teacher staff meeting, the meeting is most likely to occur in September and exclude nonteaching school staff members such as educational assistants, secretaries, or custodial staff. My study finding aligns with Ercan et al.'s (2007) report that educators feel unprepared to respond in anaphylactic emergencies.

Food sharing policies. Regarding food policies and restrictions in place in schools, my study participants' experiences seem to mirror those which are documented in the literature. For example, the three educators and three girls who participated in my research indicated that food policies do exist to help keep individuals with food allergies safe at school. Like Russell and Huber's (2013) study which indicates the most common food ban is peanuts, all 10 of my participants noted that nut products, and peanuts in particular, are banned in their respective schools. As I discovered in food allergy literature, there are those like Christakis (2008) who oppose food restrictions in schools. Similarly, I also learned from my participants that not all members of their school communities agree with the no food for sharing policies.

School environment and safe-space concerns brought to my attention by parents and children highlighted segregated seating, separate rooms, and the lack of safe spaces to eat lunch—all of which have been previously documented in the literature (Waggoner, 2013). The perception of high schools as "less protected environments" (Fenton et al., 2011, p. 177) is directly in line with my study findings where educators, parents, and the child/teen participants all spoke of the differences between the elementary and secondary school settings with regards to the implementation, monitoring, and compliance with food allergy policies.

Peer interaction. Unfortunately, two of the girls in my study have been teased by peers because of their allergies and had foods containing their trigger allergens waved at them in a threatening manner. Sadly, being teased and/or bullied has also been the experience for other
allergen-vulnerable individuals whose stories are already documented in the extant literature around allergy and anaphylaxis (Shemesh et al., 2013; see also Landau, 2010). It is also the case for my child/teen participants to have felt disregarded by their teachers in relation to their food allergies—more specifically when they were excluded from classroom activities or celebrations. Being or feeling disregarded has already been documented by Marklund et al. (2007) in their qualitative study of adolescents' experiences of food allergy.

Time, Trust, and Transition: Subthemes Revisited

These three subthemes that thread through my discussion of the five major themes have, in my view, an independent and collective significance worth revisiting. Here I consider each subtheme as an individual strand before addressing their complex interrelationship.

Time changes everything. The concept of time seems to pervade all aspects of life with a food allergy and was most frequently referred to by the *parent* participants in my study. In its simplest form, time was viewed by parents as a quantitative consumptive measure of how long something takes to occur (Williams et al., 2009). For example, parents reported: (a) the length of time and chronological age of their children as pertaining to medical appointments and the acquisition of an allergy diagnosis; (b) the amount of time spent "shopping," "label reading," "cooking," "baking," "cleaning," and "disinfecting" to ensure a safe home environment; (c) the preparation time required to ensure the social inclusion of their children in regular activities such as parties with friends, athletics, or family travel; and (d) the amount of time engaged in education and advocacy behaviours like talking or meeting with school staff members, writing letters, completing forms, volunteering at school, and attending field trips or school-related functions. Parents also spoke of time in terms of planning and scheduling—notably around

being "back home for dinner time," as well as when to try new foods (both parents present) and the wait time intervals used when introducing new food items ("15," "20," and "30" minutes).

When the child/teen participants in my study spoke of time, it seemed they referred most often to significant *moments* in time. For example, the girls recalled negative allergic reaction stories and memories and recounted incidents where they felt different or were teased because of their food allergies. The girls also recalled positive moments where they felt special because of their allergies—for example when Robyn was recognized in school by teachers she did not know, or when Ashley's friend organized a dinner with attention to Ashley's allergies.

In urgent moments when time was of the essence, its passage seemed to slow as evidenced by participants' detailed descriptions of potentially life-threatening incidents and/or emergency situations. For example, when: (a) Megan and Diane recalled the oral food challenge test; (b) Barb remembered racing home to administer medication to Robyn during a reaction; (c) Ashley shared the story of her immediate reaction upon entering a restaurant; and (d) Angela acknowledged hesitating in the seconds before injecting a student with epinephrine. The passage of time was used in a more general way by educators to contextualize policy and practice changes that have occurred in schools "over time" and have influenced how individuals with food-induced allergies and anaphylaxis are treated in schools. As well, educators considered time as related to training and supervisory duties. Specifically, they addressed: (a) the time of year when anaphylaxis training occurs; (b) the lack of time dedicated to food allergy emergency response training; (c) the amount of time devoted to inclusion planning and communication with school community members; (d) the time spent monitoring food consumption of students; and (e) the times during the school day when teachers are scheduled away from their students.

Trust of self and others. Two primary aspects of trust emerged during my research study—*trust of self* and *trust of others*. A third facet of trust—*place*, was also noted. In my view, from the outset of my work, trust has been the quintessential expression of care around my research into the school experiences of students with life-threatening food allergies and anaphylaxis. As a researcher, my study participants have entrusted me with personal and healthsensitive information-and for that I feel it is my ethical responsibility to adhere to the highest ethical standards in the design and implementation of my study (see also Chapter Three). As an individual who does not have food allergies and is not a school administrator, I was an outsider in my relationships with my participants (Dwyer & Buckle, 2009). I feel however that the proximity to my insider roles as parent and educator did afford me a degree of trust that another researcher without similar life roles or experiences may not have had (Glesne 2006, 2011). At times, my multiple roles required me to make best interests ethical decisions around which data pieces to include in, or exclude from, my study (Shapiro & Stefkovich, 2005). This was especially important where my own daughter Ashley's interview data was concerned, as she is the only participant whose real name was used in my study. For example, in her interview, Ashley shared what I believe to be a very powerful betrayal of trust experience that for her, has had a profound emotional impact. I intentionally avoided detailing the account as the specificity of the situation and the ethical disconnect therein would undoubtedly have identified the individuals involved, which could in turn result in further negative consequences for Ashley or others.

Self-trust. For the girls in my study, trust of self, manifested as both *knowing* and *doing*, and was reflected in the identity and strategy themes. The first aspect of trust of self pertains to a physical awareness of self; a recognition and acknowledgement of the signs and symptoms being

experienced. In their interviews, all three girls shared what typically happens to them when they have a reaction, and I learned that each girl is hyper-alert to the physical responses their bodies produce when they encounter a trigger allergen. In *The body remembers*, recall, Ashley "just knew" that something was wrong. This awareness, however, requires an action, and all three girls could articulate what they *do* to help themselves when in allergic distress. The second aspect of trust of self also relates to doing, but it is more of an internal self-control than a response to a physical symptom. Robyn spoke of resisting temptation and having to "talk sense into [her]self" when she sees something that she wants to eat but doesn't know the ingredients. Trust of self in this sense requires knowledge, motivation, and the fortitude to follow through.

Trusting others. The trust of others dominated participant perspectives in all five themes of my study. In terms of identity, trusting relationships seem to be a source of self-knowledge. For example, the girls did not necessarily remember their early allergy experiences but they did acquire stories and information from trusted family members that they subsequently integrated into their allergy identities. Regarding the identification of food allergens on product labels, participants *depend* on others to communicate through labels and *rely* on the accuracy of labelling when making consumption decisions. Perhaps the most pervasive expression of trust of others, however, related to school communications, whereby parents of students with life-threatening allergies are trusting "everybody . . . to do the right thing" as Angela so eloquently stated. Child/teen participants in my study reported experiencing a *betrayal of trust* when they were called names, teased, or threatened with food items containing their trigger allergens.

Safe at home. The notion of home as a trusted place was central to the discussion around the rules, routines, and safe-care strategies theme. The teens in my study also talked about avoiding places they did not trust, like the school cafeteria. As well, they avoided going to

restaurants with friends or planned to arrive at social gatherings "after supper" in order to evade "awkward" encounters. It seemed to me that trust of place conversation threads were at times less about the actual physical spaces and more about the trust of others accompanying the spaces. Take for example, Ashley's admission that she considers who else is attending a field trip and distance to the nearest hospital before she makes a participation decision. At times, proximity to trusted individuals seems to be an aspect of trust of place, as in Kim's case where she did not feel comfortable allowing her son to travel out of country on a school trip.

Transitions. For the participants in my study, transition was most often conceptualized as a linear movement in space or time, from known or familiar identities, roles, relationships, behaviours, routines, experiences, and situations toward their less familiar or unknown counterparts. Becoming new parents, coping with their child's ill health, and acquiring a food allergy diagnosis were identified as stages of acceptance of parents' new realities and identities as "allergy parents" which required them to transition from established to new ways of thinking, being, and doing. For example, after learning of their children's food allergies, parent participants all reported developing a new "awareness" that involves careful planning, tireless advocacy, and "constant" communication. As well, comfortable individual and familial routines and/or behaviours were augmented or replaced to include attention to food safety, something that was perhaps not previously required. For example, in the responsibility and safe-care strategies theme, participants spoke of labelling food items in their refrigerators, preparing separate meals for family members, bringing food with them when they were required to eat away from home, overseeing aspects of food preparation when at family holiday dinners, and adhering to rigid cleaning routines. These strategies were not utilized before learning of food allergies.

For the child/teen participants, transition was most frequently referred to in the context of concrete experiences like trying new food items, going to new places, or socializing with new people. The girls in my study seemed more willing to experience transitions when trusted communication and autonomy support strategies were in place (Williams et al., 2009). Regarding trying new food items, the transition was represented by a gradual process participants used when determining if an allergen was offensive or not. Going to new places, socializing with new people, or venturing out independent of their parents was an easier transition for the girls when they had immediate access to their medication and phones for communication purposes. The purse was a recognized support strategy that connoted both the transfer of responsibility from parent to child as well as the move toward more independence.

The change from elementary to secondary school was talked about by all participants as a major transition where not only the school environment was different, but the allergy-related policies and practices as well. Almost all participants who addressed the policy-to-practice gaps, noted a certain disregard for the rules and a lack of policy enforcement in secondary schools. For educators, transition conversations also included clarifying for some members of the school community (who do not have food allergies) the policies and behavioural expectations around food allergies. For Ashley, Megan, and Robyn, transitioning from elementary to secondary school has meant assuming more personal responsibility for aspects of their own care, including risk assessment, decision-making, and advocacy. Further, the teens and their parents expressed concern about transitioning to postsecondary school as well, as doing so may mean venturing away from the comfort and safety of home, as was discussed in the communication theme.

Symbolic representations of time, trust, and transition. At the end of each of my five themes, I included a discussion of an image (or two), which for me seemed to visually represent

the theme. In review: (a) identity was represented by the EpiPen®; (b) responsibility and safecare strategies by the purse; (c) labels and labelling by the MedicAlert®; (d) communication by the cell phone; and (e) ethical disconnects by the images of the locked cupboard and the loaded gun. Here, I explain how each image representing a major theme in my study is also connected to one or more of the subthemes. For example, the EpiPen® and the cell phone are tools that can provide *time* to live or timely access to potentially life-saving care. I might argue that the MedicAlert® bracelet also has the potential to provide access to emergency supports in a timely fashion; however, in my study, I viewed it as a missing label and do not feel it had the same significance to my study participants as the other two tools did.

Regarding trust, I feel the Epipen®, purse, MedicAlert®, and cell phone seem to provide participants with some degree of comfort or security. Of the four symbols associated with trust, the purse seemed to represent a *trusted strategy* by which the girls could discretely transport their trusted life-saving tools. With respect to transition, the management responsibility associated with carrying a purse and a cell phone connote a rite of passage from childhood into adolescence—from dependence to independence. Noted by Grant to be a symbol of maturity, the purse is a socially accepted autonomy support strategy (Williams et al., 2009) that allows for some degree of freedom and movement away from familiar safe spaces to new environments.

Interrelationship: Time, Trust, and Transition. When considered together, my three subthemes highlight the complexity of an interconnected and interdependent relationship between and among the concepts of time, trust, and transition. As trust of oneself and others develops over time, transitions may become less troublesome for individuals with food allergies.

Implications for Practice: Ethical Calls to Action

The best interests of the student model positions the individual student at the centre of ethical decision-making where the ethics of critique, justice, the profession, and care are applied in practice (Shapiro & Stefkovich, 2005; Stefkovich, 2006; Stefkovich & Begley, 2007). Here, I focus on the ethical disconnects in schools as identified by my study participants and offer suggestions from them as possible solution-focused strategies for school leaders and communities to employ. I enter into the conversation, however, with a challenge for any reader to learn more about allergy and anaphylaxis in their own communities of practice.

Ethic of Critique in Practice: Listen to Students

An ethic of critique would suggest that students with life-threatening food-induced allergies and anaphylaxis should be engaged in communication and decision-making as related to their own best interests (Freire, 1970/2005; Shapiro & Stefkovich, 2005; Starratt, 1994; Stefkovich, 2006). With respect to my study, I observed a disconnect between parent and child perceptions of allergy awareness at schools, specifically noted in my communication theme. I found it troubling when Megan shared that she did not know if her teachers knew of her allergies, though my interviews with her parents indicated her teachers were informed (see *Policies and students: Who knows?*). From a critical perspective: What are the unstated values that exist in a school where students with serious food allergies are not certain if their teachers know they have allergies? Who has the power to change communication protocols around allergy and anaphylaxis in schools? Further, how might school leaders empower students with allergies to advocacy, if said students happen to not want any added attention? Megan's aforementioned recommendation that students, teachers, and administrators meet to discuss an individual's food allergies, in my view, is a good one; however institutional and/or familial

power structures might suggest that the adults, more specifically the school administrators, ought to extend the conversation invitation to students and their families.

Ethic of Justice in Practice: Assume Responsibility to Educate

In a broad sense, the ethic of justice is concerned with laws, polices, and rights (Shapiro & Stefkovich, 2005). When considered in the context of my study, I perceived a gap in the consistent application of Sabrina's Law as pertaining to staff allergy and anaphylaxis training as explored in my ethical disconnects theme. It seems that inconsistent application of food allergy legislation, policies, and training provisions in schools and boards have resulted in uncertainty for staff, students, and families. Some may be troubled that Angela has not been a part of staff allergy and anaphylaxis training for the last few years despite knowing there are children in her school with life-threatening food allergies. Similarly, some might be disturbed to learn from Carolyn, Angela, and Barb that contract lunch supervisors and the grade 5–8 student lunch monitors who have supervisory responsibilities for children and classes over the nutrition breaks seem to have the *least* amount of training. From a justice perspective: Is allergy and anaphylaxis training being provided to all school staff, regardless of employee role? Are there school and board policies that need to be communicated or enforced and, if so, to whom and by whom? Is the school or board in need of a new policy or set of guiding principles? Could teacher supervision and/or preparation time schedules be reconsidered so that they simultaneously adhere to contractual obligations and meet a standard of supervisory care during the potentially high-risk nutrition breaks? Carolyn's in-action interview reflections pointed to the need for regular and consistent allergy awareness education and training for all: teaching and nonteaching staff members, students in leadership or supervisory positions, and school administrators as they are charged with the responsibility to provide such training in practice.

Ethic of the Profession in Practice: Reflect and Act

The ethic of the profession considers "those moral aspects unique to the [education] profession" within the context of "personal and professional codes of ethics" (Shapiro & Stefkovich, 2005, p. 19). When the experiences shared by the participants in my study are viewed through the guiding documents of the Ontario Ministry of Education and the Ontario College of Teachers (see previous discussion in Ethic of the Profession: A Review of Select Documents), concerns arise. Tina, Angela, and Barb all reported that their respective schools host food fundraisers, wherein some food items contain the trigger allergens of some of the students in their school communities. Barb's account of nut-containing cookie dough being promoted by staff and students at her daughter Robyn's school seems disconcerting. Likewise, Angela's story of staff members who bring "contraband" allergens in their own lunches or on professional activity days is not only unsafe but also disrespectful. From a professional viewpoint: Are educational values being compromised by the decisions made and/or the actions permitted in schools? Are the ethics of care, respect, trust, and integrity as outlined in the Ontario College of Teachers' Ethical Standards for the Teaching Profession (2015a) being adhered to? Is "student vulnerability" being recognized, and are actions being taken to "mitigate" that vulnerability (Ontario College of Teachers, 2015a, p. 3)? Would members of the school community expect the same rules apply for students and teachers? Barb offered a simple solution to the food fundraiser issue when she suggested a different dough supplier be found (though school administration did not agree). Angela's contraband issue seems to be a conflict between professional and personal codes of ethics where some staff members either do not agree and will not comply with the school policy, or perhaps do not understand the complexity of risk associated with life-threatening food allergies and anaphylaxis.

Ethic of Care in Practice: Model Respect and Safe-Care

An ethic of care centres around how relationships are created and maintained (Noddings, 2013). With respect to my research study, the ethic of care is perhaps the fundamental ethic on which the other ethics of critique, justice, and the profession are formed. While one could reconsider the aforementioned ethical calls to action through the paradigmatic care lens, instead one might turn attention to a call to action that will require the consideration and modelling of respectful care in practice. Although Angela (and to a lesser degree, Tina) reported purposeful planning of the learning activities in her classroom with allergies and anaphylaxis in mind, such practice did not seem to be the experience of the girls who at times felt excluded by their teachers' inclusion of food (without notice) in classroom activities. In perhaps a more concerning value-laden example where both trust and safety were compromised, one might recall Robyn's teacher who, on three separate occasions, encouraged her to enjoy a food treat that had not been "mom-approved" by Barb. From an ethic of care perspective, reflective questions one might ask include: Why and for what purpose is the instructional (policy, practice, or response) decision being made? Might this decision intentionally or unintentionally exclude or hurt someone physically, socially, or emotionally? What could be done instead to promote inclusion? Might individual/group actions or decisions affect the relationships or betray the trust of individuals with life-threatening food allergies? What is the effect on students who observe "genuine caring done by adults" on a regular basis (Noddings, 2013)? A simple suggestion from participants to adhere to individual and school-based rules could circumvent situations like Robyn experienced. Similarly, consistent application and enforcement of anaphylaxis policy from elementary to secondary school could also reduce safety and care vulnerabilities as addressed in the Locked and Loaded: The Cupboard and the Gun ethical disconnect discussion.

Possible Importance of the Study

As a parent, educator, and researcher, I feel my study has, perhaps, some value beyond its intended scope and that others who happen upon my work may empathize, respond, or act in numerous ways unknown to me. Here, in the subsections below, I highlight for the reader some advantages my study may have for my 10 individual participants therein and for society at large.

Potential Benefits for Participants

I anticipate that all participants may have benefitted in some way from sharing their perceptions, insights, stories, and strategies around the school experiences of children with food allergies and anaphylaxis (Kvale & Brinkmann, 2009). As well, I believe that all participants, individually and collectively, identified and/or illuminated perceived gaps in the policies, procedures, and practices around allergy and anaphylaxis management and care in schools.

Some participants might have appreciated that a researcher with both familial and education-related allergy experiences was interested in learning from them. Specifically, children/teen participants may have been pleased that a researcher was interested in their individual experiences living with and negotiating daily life with a food allergy from an education and interpersonal perspective instead of a strictly medical view. During the transcript review process, my own daughter added a note of encouragement and thanks for the "opportunity," adding that she felt she was "finally getting to have a voice," which was particularly touching to me as her mother and researcher. At the same time, my daughter's transcript revision note made me feel sad (as her mother and an educator) that she does not feel her voice has really been heard.

Parent participants might have benefitted from sharing personal stories, thoughts, feelings, and experiences of raising a child with food allergies. I felt that at times during the

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parent interviews, I drifted between two personas—the *outsider* researcher and *insider* mother (Dwyer & Buckle, 2009). On more than one occasion during the parent interviews, I felt a sense of kinship with the parents, particularly when I asked for more details about a strategy the individual parents employed to keep their children safe. Some of the experiences and strategies participants shared were familiar to me and others were new ideas that I might adapt for use. Parent participants might be pleased that a researcher and mother of a child with food allergies is learning from their personal experiences parenting a child with food allergies.

Teacher and administrator participants may have benefitted from sharing their experiences meeting the needs of all students when they have a child with food allergies in attendance at their school or in their classes. The teachers may appreciate that another educator (who happens to be a researcher and the parent of a child with food allergies) values the time, effort, thought, and care that they put into their planning to ensure students with food allergies stay safe at school. In particular, Angela might have appreciated having had the opportunity to talk about her emotional experience having to administer an epinephrine auto-injector to a student at school. Carolyn seemed grateful to have had the opportunity to reflect in and on action, in her discussion of student and staff allergy awareness training (Schön, 1983, 1987).

Potential Benefits to Society

I anticipate that my study may contribute in some small way to the extant literature around food allergy and anaphylaxis in schools; more specifically, to a collaborative and ethical approach to allergy awareness, care, management, and training in the educative arena. Children or teens who have life-threatening food allergies (and were not participants in my study) may: (a) feel their own experiences have value; (b) appreciate learning about the experiences of other children or teens in similar situations; or (c) be empowered to self-advocate or voice concerns about allergies and anaphylaxis practices in schools. Parents may find my study useful as a reference when they first learn about their child's food allergy by previewing potential issues they may encounter and possible strategies they might utilize. Parents may turn to my study to learn how others negotiated challenging situations and may feel that the voices in my study offer promising solutions and/or hope.

Teachers may reflect on their own professional practice and incorporate some of the inclusion strategies shared by my study participants. Educators may find they can more easily address some of the concerns that parents of children with food allergies face sending their children to school each day. School administrators and educational leaders who read my work may be inspired to collaborate with students and their parents to review and/or revise their respective institution's policies and procedures. The medical community may find my study useful in some small way as it identifies some of the common physical, social, and emotional concerns that children/teens with food allergies and anaphylaxis (and their parents) face that quantitative studies do not address (Gallagher et al., 2009; Morse, 2013; Rouf et al., 2011). Medical personnel who happen upon my research study may read it and share it with others in their personal or professional networks. In a very general sense, it is my hope that anyone who reads my study finishes it with a better understanding of the some of the daily life challenges that individuals with food-induced allergies face and some of the safe-care support strategies that might improve an aspect of their physical, social, emotional, or academic lives.

Strengths of My Study

To the best of my current knowledge, my qualitative case study around the school experiences of students with life-threatening food-induced allergies and anaphylaxis is the only research of its kind in Ontario that considers the perspectives of children, parents, teachers, and

an administrator in the *same* study. As I immersed myself in the extant literature around food allergy and anaphylaxis in schools, I discovered it is dominated by quantitative studies with school policy and procedural recommendations being offered by medical professionals (Gallagher et al., 2009; see also Morse, 2013). I feel a strength of my study is that I offer *voice* to some individuals who *live* allergy and anaphylaxis (Mitra, 2012; Van Manen, 1990) as well as to those who make ethical decisions on their behalf (Shapiro & Stefkovich, 2005).

It was important to me to understand my study participants' emic perspectives and meanings in context (Glesne, 2011; Kvale & Brinkmann, 2009; Mason, 2002; Maxwell, 2002; Merriam, 2009). As such, I feel that I was able to create rich and thick descriptions of the complex lived realities and daily experiences of individuals with food allergies that ultimately provided contextual and foundational perspectives that served to ground and support the descriptions of school-related experiences which followed (Denzin & Lincoln, 2005; Glesne, 2011; Merriam, 2009; Patton, 2002). I believe my study to be heuristic in that participants provided insight, offered meaningful suggestions, and generated new ways of knowing, understanding, and thinking about food allergy and anaphylaxis (Merriam, 1998; see also Amulya, 2011; Doll, 1993). By doing so, I feel my study offers individuals, school community members, and decision-makers a starting point for *reflection* and *action*. Educational leaders, either formal or informal, who reflect on action or in action may have the ability to transform policies, procedures, and practices in schools to better the physical, social, emotional, and academic best interests of individual students with life-threatening food allergies and anaphylaxis (Schön, 1983, 1987; see also Marlowe & Page, 1998; Mezirow, 1990; Molz & Edwards, 2013; Noddings, 2012a; 2013; Shapiro & Stefkovich, 2005; Stefkovich, 2006; Stefkovich & Begley, 2007).

Limitations of My Study

As with any research study, there are bound to be challenges. Below, I share the methodological and procedural limitations I encountered during my research process. I attend to how my study topic might have invited participants with a particular interest, view, or bias about the school experiences of children with severe food allergies. I outline technical difficulties and unexpected circumstances that occurred and discuss how they might have affected my study.

Methodological and Procedural Limitations

My qualitative research study was designed to uncover the student, parent, teacher, and administrator perceptions of the school experiences of students with life-threatening food allergies and anaphylaxis. I am fully aware that my research interests, and ultimately my choice of study topic, have grown from my lived experience as a parent of a child with food allergies and have been informed by my professional practice as a secondary school educator (Van Manen, 1990). Despite audio-recording all participant interviews, asking participants to expand or clarify ideas, and ensuring that all participants had opportunity to review their transcripts for accuracy and intended meaning, I acknowledge that as a qualitative researcher I am "firmly in all aspects of the research process" (Dwyer & Buckle, 2009, p. 61). Ultimately, all of the data in my research study is being filtered through my own worldview and researcher lens (Creswell, 2008; Glesne, 2006, 2011; Merriam, 1998, 2009), which could be perceived as limiting.

All potential study participants who responded positively to my initial contact telephone call or email had the ability to self-eliminate from my study by indicating they were not interested in reviewing a Participant Information Letter and Consent Form (Seidman, 2006, 2013). Similarly, participant self-elimination from my study could have occurred following the review of the Participant Information Letter and Consent Form if individuals felt they did not want to volunteer to be in the study (Seidman, 2006, 2013). As I required the written and informed consent of each individual who agreed to participate in an audio-recorded in-depth interview (as well as the written and informed consent of a parent in the case of minor participants), people could have declined and therefore self-eliminated from my study (Seidman, 2006, 2013). Participant consent to take part in my research study could then indicate a particular interest, bias, or perspective that could be perceived as limiting (Seidman 2006, 2013).

As my research study progressed, I noted three other matters that could be perceived as a limiting. First, nine of the 10 participants in my study were female (all children, all educators, and three of the four parents). While I had hoped that at least one teen male with food allergies would volunteer to participate in my study, the gender imbalance in my personal allergy-related contacts suggested to me that it was possible that more females than males might participate. As allergy is such a personal and sensitive topic, my position as a female researcher (and mother) may have been, in some way, a self-elimination aspect that some potential male participants might have considered. Similarly, food allergy quality of life research has focused on the roles of mothers as primary caregivers to children with food allergies (Warren et al., 2015; see also Bartnikas & Phipatanakul, 2015; Rouf et al., 2011), so I was not surprised that I had more mothers than fathers agree to participate in my study. Second, my research could be perceived as limiting because I interviewed only individuals who had experience with or were associated with English Public or English Catholic school boards (no French public/Catholic, private, or homeschool perspectives were represented). Third, all three educator participants had at least 18 years of teaching experience (no supply teachers or early-career teachers participated in my study). I would suggest, then, that if had I used a different sample selection technique I might have recruited a different group of individuals with different allergy and/or school experiences.

Technical Difficulties

I encountered only one technical difficulty during data collection—I unknowingly pressed "play" instead of "record" after turning an audio-tape to its second side. As a researcher, I had had this experience happen during a previous unrelated project, so this time I recorded all participant interviews using two recording devices. I did not lose access to any participant data.

Unexpected Circumstances

As a researcher, I am aware that anything can happen during the course of an interview and, even though I anticipated some potential issues and worked to avoid them—a few minor unexpected occurrences happened. Where I had some control over the interview environment, I ensured that all extraneous people were away from, and pets were removed from, the interview space to avoid possible distractions. Similarly, I unplugged phones or powered off electronic devices to reduce the possibility of disruptive noises. Where I was a guest in participants' homes, however, I did not feel comfortable asking them to remove pets from the interview space, nor did I feel comfortable asking adult participants to refrain from addressing a child who poked her/his head into the interview room to ask a quick question. Similarly, when adult participants brought cell phones to their interviews, I did not ask them to put their phones on mute (even though one participant did). I recognized and respected that adult participants, perhaps especially as parents of children with life-threatening allergies, might have reason to require their phones during their interviews—perhaps so their children could access them or for personal access to a clock to ensure they could attend to scheduled commitments that followed the interview (which was the case for two parent participants in my study). I did not perceive cell phones to be a concern during the actual interviews however, as I was listening to Diane's audiorecording, I did hear her voice quicken ever so slightly and momentarily following the receipt of

a text message from her child. Although her child could not have heard it, Diane offered a verbal acknowledgement and apology during the interview, saying "yes, I know Megan and I'm sorry" which could have been an expression of urgency to me to complete the interview. In reviewing the transcript, I saw that my final open-ended question followed quickly thereafter, which indicates that, whether intended for me or not, I picked up on the cue. What is intriguing to me is that even though I presented Diane with the opportunity to end the interview, she continued on for 11 more minutes touching on: her concern for Megan's future, her trust in Megan's ability to make good decisions, Megan's social acceptance at school, as well as the time that is required to "trust" others and her own parental "anxiety" in ensuring Megan's safety.

Late arrivals. Unforeseen personal circumstances resulted in two of the adult participants arriving late to their respective interviews. While this was not a problem for me (as I had made arrangements to clear my personal schedule for both evenings), I sensed that both individuals felt they had inconvenienced me by their unexpected delays. I did my best to reassure each participant that it was not a problem and that I appreciated they were still able to attend. In addition, I inquired as to whether either individual had a commitment following our interview that would change the amount of time we had together—neither did, and both interviews progressed as planned. What I had not anticipated however was the lengthy, more social conversations (largely unrelated to my research study) that took place following each of these two interviews. In the moment, I felt these two post-interview conversations were relaxed and enjoyable, but afterwards I noticed the similar structure of the interviews and wondered if the participants had felt compelled to stay, perhaps to make up time or as a way to strengthen rapport (Seidman, 2013).

Within earshot. When interviewing minor participants, I required a parent to be present in the interview location for the comfort and safety of both the child/teen participant and myself. I did request that the accompanying parent not be present in the interview room as the child/teen's responses might differ if the parent were to stay in the room. Similarly, where a child/teen participant and her parent both agreed to be interviewed and requested back-to-back interview times in the family home, I requested that the child not be in the room when the parent was being interviewed. While these requests were, in my view, technically honoured, the open concept layout of one family's home did allow for the child to have a clear view of her mother in the adjoining room, and my field journal notes indicate that on more than one occasion during her interview, the child looked to her mom, seemingly to determine if her mother had heard her response and/or to see if her mother approved of her response. In one instance when the daughter was having trouble recalling the name of a restaurant, her mother called out the restaurant name (from the adjoining room). I was initially taken aback by the interjection but then rationalized that the mom was being supportive of her daughter who, in the first few minutes of her interview, might have been little nervous, and the mom thought nothing of it.

I did not anticipate that, when it was the mother's turn to be interviewed, she would, at various moments, call out to her children (who were in adjoining rooms), inviting them to help her out with information she could not immediately recall. It was a very interesting dynamic to observe, and while I did not at first understand why it was happening, I did get a clear sense of the familial awareness and ownership of her daughter's allergy. Upwards of 15 times during the mother's interview (and seemingly without losing her train of thought I noticed in the transcription), the mom addressed the family dog multiple times about his behaviour and two of her children about their evening routines. At one point during the interview, I offered to pause

the audio-recording so that the mom could say goodnight to her youngest child. In that moment, I felt bad for infringing on what I perceived to be special family time and recalled our preinterview conversation where I asked the mom if she still felt we had enough time to do the interview and she responded positively. It was only then, when both children were away from the interview area, that I perceived the mom felt she could access her inner voice (Steiner, 1978). She spoke openly about: future limitations or restrictions her daughter may encounter, removing her daughter from challenging social situations where food has been an issue, her own advocacy in schools for her daughter and others with food allergies, the multiple and varied expressions of food allergy, and her own uncertainty in knowing when to *pen* her child.

Recommendations for Future Research

The scope of my qualitative case study centred around the school experiences of students with life-threatening food-induced allergies and anaphylaxis as perceived by children, parents, teachers, and an administrator. In using a purposive sample of convenience (Merriam, 1998) to invite individuals to participate in my study, I am aware that other, perhaps different voices, and experiences might have been excluded. Here, I share my recommendations for future research.

Honour the Voices of Other Children and/or Teens

All of the children who participated in my study (or who were mentioned by parents in my study) learned of their allergies at a very young age. I wonder if the daily life and school experiences for children/teens who develop a food allergy *after* entering elementary or secondary school, are similar or different from those of my study participants. There may be a research opportunity to be explored in this regard. Similarly, children/teens with life-threatening allergies to nonfood items, such as stings, medication, or latex, were not the focus of my study; however their voices would contribute to the allergy and anaphylaxis discourse in education.

As I did not have any male children/teen participants in my study, my subsequent findings did not include the allergy experiences of any male students. I wonder if male child/teen participants would have reported experiences that were similar to or different from the girls in my study, specifically around individual identity, relationships with family and friends, or communication strategies. Similarly, I did not have any postsecondary students or teens with experience living away from parents (either off campus or in residence) participate in my study. I feel the growing population of individuals with life-threatening food allergies and anaphylaxis will soon require postsecondary institutions to review their policies, procedures, and practices.

Listen to Siblings, Parents, and Grandparents

As I am the parent of two children, one of whom has food allergies and one who does not, I often wonder how the sibling(s) without food allergies craft their individual identities within the family. All of the children with allergies mentioned in my study were firstborn, and I feel it would be interesting to interview second or later born children with food allergies to see if their experiences are similar to or different from the individuals in my study.

All of the parent participants in my study were married and living with their respective spouses and children. Given the amount of time that the participants in my study indicated is required to ensure the safety and inclusion of their children with food allergies, I wonder how single-parent-led families might manage the daily restrictions that food allergies impose. I would be interested in learning from parents who have chosen to homeschool their children as a result of an unfavourable treatment in a traditional public or private school setting. I would also argue that the voices of fathers who have children with food allergies are underrepresented in the extant allergy literature. An exploration of the genetics of food allergy could be an area of research, given two fathers of the three girls I interviewed have food allergies.

There is opportunity to deepen understanding of familial supports and relationships that sustain the core family unit. In particular, I am thinking about the role that grandparents (and perhaps other extended family members) play in supporting the parents of children with food allergies and the children themselves. I am curious to learn more about mental health and wellbeing of children with food allergies and their family members, as I feel the participants in my study alluded to aspects of psycho-social quality of life but did not make this a focus of the interview conversations. I anticipate there is much to learn in this regard.

Identify and Act on the Training Needs of School Staff Members

I did not have any teachers in my study who had experience with more than one student in their classroom at any one time with food allergies. It might be worthwhile to learn how teachers negotiate daily routines with multiple students with (similar or different) food allergies in their classrooms. The teachers in my study were experienced educators with full-time employment. It might be interesting to see if the perceptions of teachers with relatively less teaching experience would yield similar results. One might expect that supply teachers, who are not often assigned to one school, would have insight about training and communication they require to support students with life-threatening food allergies in schools. I am also curious about the supports that pre-service teachers acquire in their education classes. Although both teachers in my study reported having food allergies themselves, neither seemed to indicate this was a barrier to their employment. I wonder if teachers who have food allergies and are new to the teaching profession have found their allergies to be a barrier to permanent employment or a benefit as they might bring a measure of awareness and expertise.

My study revealed that there are gaps in the implementation of anaphylaxis policy into practice, specifically around staff training in schools. I learned from Carolyn that secretaries and educational assistants are often the front-line school employees who deal with allergy-related emergencies in schools. A qualitative research opportunity could focus around the training, support, and involvement that secretaries, educational assistants, and custodians have with respect to students with food allergies and anaphylaxis. It might be interesting to conduct a study specific to school administrators around the training they receive to support students with life-threatening food-induced allergies. Does a training module currently exist, or could one be created and added to the Principal Qualification Program? Do administrators feel prepared for the responsibility that is food allergy and anaphylaxis? Do they provide training beyond the *flip and jab* EpiPen® demonstration? Is there any current research around the effectiveness of online module anaphylaxis training that some schools and boards of education are purchasing? Who is vetting these online modules, and what background knowledge do they have to do so? These are but a few questions of ongoing concern.

My Final Thoughts

As a parent of a child with life-threatening food-induced allergies and anaphylaxis, and an educator, I was both an insider and an outsider in my own research study (Dwyer & Buckle, 2009). For me, the completion of my doctoral dissertation is in part a written expression of my personal, professional, and academic growth. I am filled with immense gratitude to my 10 study participants who were giving of their time and trust. They generously shared their private thoughts, feelings, stories, memories, and experiences around my study topic so that I, and others, would have the opportunity to learn, grow, and perhaps answer an ethical call to action.

> "Authentic learning . . . carries with it a responsibility to what one is studying and for what one learns" (Starratt, 2004, p. 57).

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Appendix A

Nipissing University Research Ethics Board Letter of Approval

September 08, 2016

Ms. Tiffany Roberts Schulich School of Education Nipissing University

File No: Expiry Date: September 08, 2017

Dear Tiffany,

It is our pleasure to advise you that the Research Ethics Board (REB) has reviewed your protocol titled 'The School Experiences of Children with Life-Threatening Food-Induced Allergies and Anaphylaxis as Perceived by: Children, Parents, Teachers, and School Administrators' and has granted ethical approval. Your protocol has been approved for a period of one year.

Modifications: Any changes to the approved protocol or corresponding materials must be reviewed and approved through the amendment process prior to its implementation.

Adverse/Unanticipated Event: Any adverse or unanticipated events must be reported immediately via the Research Portal.

Renewal/Final Report: Please ensure you submit an Annual Renewal or Final Report 30 days prior to the expiry date of your ethics approval. You will receive an email prompt 30 days prior to the expiry date.

Wishing you great success on the completion of your research.

Sincerely,

Dana R. Murphy, PhD Chair, Research Ethics Board

Appendix B

General Schedule of Interview Questions for Children

1. <u>Confirmation of Severe Food Allergies/Anaphylaxis</u>

The first few questions I'm going to ask you will be about your allergies:

- a. Could you please tell me what foods you are allergic to?
- b. Do you have an EpiPen® (epinephrine) for any of your food allergies? If so, which allergies?
- c. Do you have asthma, eczema, or do you often have a runny nose or itchy eyes (allergic rhinitis)?
- d. Do you remember when you first found out you had a food allergy? If so, could you tell me about finding out?
- e. Do you ever remember having an allergic reaction to food? Could you tell me what happened?

2. Daily Family Life with Food Allergies

The next few questions I'm going to ask you will be about everyday life with food allergies:

- a. What is it like for you, living with food allergies?
- b. What is it like for your family?
- c. What do you or your family members do to keep you safe at home?

3. Student Experiences

The next few questions will be about food allergies at school:

- a. What is school like for you, having food allergies?
- b. What do people at school know about your allergies? What do you think people at school don't understand about your allergies?
- c. Is there ever anything you can't do at school because of your allergies?
- d. Have you ever had an allergic reaction at school? If so, what happened? How did you feel about this?

4. <u>School Experiences of Children with Severe Food Allergies</u>

What do you feel is the hardest thing about being a student with a food allergy? What is the best thing about being a student with a food allergy?

5. Other

Is there anything else you would like to tell me about your allergies?

Appendix C

General Schedule of Interview Questions for Teens

1. Confirmation of Severe Food Allergies/Anaphylaxis

The following questions will address your food allergies and allergic reactions:

- a. Could you please tell me what you are allergic to?
- b. Do any of your allergies require you to have a prescription for epinephrine?
- c. Do you have any other allergic diseases like asthma, eczema, or allergic rhinitis?
- d. Could you tell me how you first learned that you had a food allergy?
- e. Could you tell me about your most serious allergic reaction to a food?

2. <u>Daily Family Life with Food Allergies</u>

The following questions will address how having food allergies affects daily life:

- a. How do your allergies affect your daily life?
- b. Have your food allergies affected your family? If so, how?
- c. What supports/strategies are in place in your home to keep you safe?

3. <u>Student Experiences</u>

The following questions will address what it is like to be a student with food allergies:

- a. Could you describe what a typical school day is like for you as a student with food allergies?
- b. Do your food allergies ever affect your participation in classes or in school activities? If yes, would you tell me about it?
- c. Have you ever had an allergic reaction at school? If so, please explain.
- d. What do you wish other students or adults in your school understood about being a student with food allergies?

4. <u>School Experiences of Children with Severe Food Allergies</u>

What do you feel is the most challenging and most positive aspect of being a student with a food allergy?

5. Other

Is there anything else about your allergies that you would like to talk about?

Appendix D

General Schedule of Interview Questions for Parents

- 1. Confirmation of Experience with Severe Food Allergies and Anaphylaxis
 - a. **Please tell me about your experience as a parent of a child with food allergies.** For example: confirmation of parent-child relationship (biological, adoptive, step-parent), confirmation of allergies, personal or family history/experiences with allergies, family members, age, educational background, or employment.
 - b. **Please tell me how you first learned that your child had a food allergy?** For example: location, offending allergen, child's symptoms/response, your response, subsequent allergy testing, other allergy-related diseases, or support.
- 2. <u>Daily Family Life Parenting a Child with Severe Food Allergies and Anaphylaxis</u>

The following questions will address how parenting a child with food allergies affects your daily life.

- a. Could you describe a typical day in your life/day in your child's life/day in the life of your family?
- b. What are the daily life challenges/restrictions the food allergy has brought to your family life?
- c. What, if any, are the benefits the food allergy has brought to your family?
- d. What supports/strategies are in place in your home to address the allergy?
- 3. Parental Involvement

Please outline your experiences as the parent of a child with food allergies who attends school. For example: interaction with the school administrators and teachers, advocacy for your child, paperwork, transportation, field trips or classroom special events, positive experiences, negative experiences or incidents, strategies, emergencies, greatest concerns, suggestions for schools.

4. School Experiences of Children with Severe Food Allergies

From your perspective, what do you perceive as the most challenging and the most positive aspect of parenting a student with food allergies?

5. Other

Is there anything else about this topic that you wish to add that I have not given you the opportunity to discuss?

Appendix E

General Schedule of Interview Questions for Teachers

1. <u>Confirmation of Experience with Severe Food Allergies/Anaphylaxis</u>

a. Please tell me about your experience as a classroom teacher of a child who has severe food allergies. For example: personal or family history/experiences with allergies, kinds of allergies in your classroom/school, number of allergies in your classroom/school.

2. Daily Classroom Procedures

- a. How does having a child or children in your classroom with life-threatening allergies to food affect your daily operations of your classroom? Decision-making processes? For example: epinephrine training, administration of medication, dealing with parents of allergic and non-allergic children, school food restrictions, cafeteria/food ordering options/fundraising with food, ethical decision-making, cleaning, transportation, forms, legalities, lesson planning/preparation, supply teacher preparation.
- b. Please describe the most challenging aspect(s) of your job as it pertains to children with severe food allergies?
- 3. <u>School Experiences of Children with Severe Food Allergies</u>
 - a. From your perspective, what do you perceive as the most positive and the most challenging aspect of being a child with a food allergy attending school?
 - b. How do you perceive having a severe food allergy affects the learning of the affected children? The other children in the classroom?
- 4. Other

Is there anything else about this topic that you wish to add that I have not given you the opportunity to discuss?

Appendix F

General Schedule of Interview Questions for Administrator(s)

1. <u>Confirmation of Experience with Severe Food Allergies/Anaphylaxis</u>

a. Please tell me about your experience as an administrator of a school where children have severe food allergies. For example: personal or family history/experiences with allergies, kinds of allergies in your school, number of allergies in the school.

2. Daily School Operations

- a. How does having a child or children in your school with life-threatening allergies to food affect your daily operations of the school? Decision-making processes? For example: epinephrine training procedures, administration of medication, dealing with parents of allergic and non-allergic children, school food restrictions, cafeteria/food ordering options/fundraising with food, ethical decision-making, cleaning, supply teacher training, transportation, forms, legalities.
- b. Please describe the most challenging aspect(s) of your job as it pertains to children with severe food allergies?

3. <u>School Experiences of Children with Severe Food Allergies</u>

- a. From your perspective, what do you perceive as the most positive and the most challenging aspect of being a child with a food allergy attending school?
- b. How do you perceive having a severe food allergy affects the learning of the affected children? The other children in the school?
- 4. <u>Other</u>

Is there anything else about this topic that you wish to add that I have not given you the opportunity to discuss?

Appendix G

Extended Definitions of Minor Terminology as Used in the Dissertation

Here, I provide brief working definitions for allergy-related and medical terms that I have used in the dissertation. For ease of reference, I have organized the terms alphabetically.

Aeroallergen. An allergen that is distributed by air. Some examples of aeroallergens include pollen, dust mites, cockroaches, tobacco smoke, pet dander, latex particles, and mold (Binkley, 2002; Mitman, 2007).

Adjuvant. An adjuvant is a substance that is added to a vaccine to enhance the immune system's response to the vaccine (Immunize Canada, 2015).

Adrenaline. A hormone made by the adrenal glands that increases heart and respiratory rates during times of stress or danger (Vaughn, 1941). Epinephrine is the synthetic version of adrenaline used in an emergency to treat anaphylactic reactions (Anaphylaxis Canada, 2015).

Allergen. An allergen is a substance that can cause an allergic reaction in individuals. Some examples of common allergens include: pollen, foods, drugs, insect stings, latex, animal dander, or dust (Canadian Society of Allergy and Clinical Immunology, 2014).

Allergic cascade. The term allergic cascade is used to describe a two-phase allergic reaction with the first phase of the reaction occurring immediately after exposure and lasting approximately 2 hours. The second phase of the reaction occurs about 6 hours after exposure to the allergen and is responsible for "prolonged" or "chronic" inflammation (Rosello & Huete, 2015, p. 17).

Allergic or atopic march. The allergic or atopic *march* refers to the typical sequence or progression of allergic disease from childhood eczema or food allergy associated with gastrointestinal manifestations to allergic rhinitis and/or asthma (American Academy of Allergy, Asthma & Immunology, 2015; Bergmann, Wahn et al., 1997; Garcia-Careaga & Kerner, 2005; Hon, Wang, & Leung, 2012). Sicherer (2013) predicts that over 50% of children who have

eczema or food allergies will go on to develop asthma, as subsequent exposures to offending allergens can result in manifestations of allergic disease in different body parts.

Allergic rhinitis. Caused by an exposure to a trigger allergen, allergic rhinitis is an "inflammation of the inner lining of the nose" (Binkley, 2002, p. 191), "throat" or "sinuses" (Rosello & Huete, 2015, p. 136). Common allergens that initiate an Immunoglobulin E response include: dust mites, molds, or pet dander, in addition to pollen producers such as trees, grass, flowers, or shrubs. Symptoms of allergic rhinitis could include: itchy, watery eyes; a runny or plugged nose; congestion or irritability (Rosello & Huete, 2015).

Allergic sensitization. The phase where Immunoglobulin E antibodies are produced that occurs after the initial allergen exposure but before the "elicitation" of symptoms (Ring & Möhrenschlager, 2007; see also Joneja, 2012). Only 50% of individuals who have increased levels of Immunoglobulin E antibodies will actually progress to the stage of allergic disease where allergy symptoms are triggered (Bindslev-Jensen, 1998; Ring et al., 2001; Ring & Möhrenschlager, 2007).

Angioedema. An angioedema is a skin reaction that is similar to "hives" with the exception that the swelling occurs below the surface of the skin, most often near the eyes or mouth. Angioedema is a common symptom of anaphylaxis (Shadick et al., 1999).

Angiotensin II. A human hormone that primarily serves to constrict blood vessels which can result in high blood pressure (Sweitzer, 2003). High levels of angiotensin II have been found to thicken the heart which can lead to heart disease, heart attacks, and strokes (Sweitzer, 2003).

Angiotensin-converting enzyme inhibitor (ACEI or ACE inhibitor). A prescription medication that works to relax constricted blood vessels and prevent the thickening of the heart caused by high levels of angiotensin II (Sweitzer, 2003). With respect to my study, angiotensin-

converting enzyme inhibitors can amplify inflammatory allergic responses which in turn interfere with epinephrine effectiveness ("Getting into the sting of things," 2006). Cases of fatal anaphylaxis have been documented in individuals who used angiotensin-converting enzyme inhibitor medication prior to exposure to an offending allergen, resulting in a deadly reaction (Xu et al., 2014). It is reported that approximately 1% of people have severe swelling of the throat and tongue when taking angiotensin-converting enzyme inhibitors for the first time and medical advice is to stop taking the medication (Sweitzer, 2003).

Antihistamine. An antihistamine is a drug that "blocks the action of histamine" (Binkley, 2002, p. 189) which in turn reduces the redness, itch, and swelling associated with an allergic reaction. A few common over-the-counter antihistamine brands available in Canada include: Allegra®, Benadryl®, Claritin®, and Reactine®.

Antitoxin. A curative substance that is used to eliminate a toxin in the body. Dr. Emil von Behring created the first diphtheria antitoxin in 1894 after immunizing horses against diphtheria (Vaughn, 1941). In the early decades of the 20th century, mass injections were being given for scarlet fever, tetanus, and diphtheria which sometimes resulted in serum sickness or disease (Vaughn, 1941). The incidence of serum sickness that sometimes ensued following an antitoxin injection lends support to the theory that anaphylaxis is a human-made malady (Vaughn, 1941).

Asthma. Asthma is a chronic lung condition that is manifests as "inflammation, constriction of the muscles surrounding the airways and excess mucus production" (Canadian Society of Allergy and Clinical Immunology, 2014, p. 58). Individuals who suffer from asthma have inflammation of the bronchi that can manifest as coughing, wheezing, or shortness of breath (Canadian Society of Allergy and Clinical Immunology, 2014; Rosello & Huete, 2015). Asthma puffers. Colloquial term to describe the group of inhaled medications used to treat symptoms of asthma (see *Bronchodilators* definition below).

Atopic dermatitis. Also known as atopic or allergic eczema, atopic dermatitis is a *chronic* condition where the skin is inflamed, dry, red, itchy, and may have small blisters (Binkley, 2002; Sicherer, 2013). Common irritants that can trigger atopic dermatitis include: low humidity, seasonal allergies, cold weather, soaps, or lotions.

Atopy. The genetic predisposition of individuals to develop Immunoglobulin Emediated allergic diseases such as asthma, allergic rhinitis, atopic dermatitis (American Academy of Allergy, Asthma & Immunology, 2015; Garcia-Careaga & Kerner, 2005).

Beta-adrenergic blocker. A drug that comes in oral or ocular forms and is used to treat a range of medical conditions, such as: arrhythmia, high blood pressure, angina, overactive thyroid, migraines, or glaucoma (Toogood, 1987). Beta blocking drugs essentially alter or block the effect of epinephrine which during an anaphylactic reaction can result in a decreased heart rate and increased tightening of the airways (Toogood, 1987). Pertaining to my study, death due to anaphylaxis has been documented in individuals who were on a beta-adrenergic blocking medication when they were exposed to a trigger allergen and subsequently experienced an allergic reaction (Xu et al., 2014; see also Lieberman & Simons, 2015; Toogood, 1987).

Beta-lactoglobulin (BLG). The whey protein in cow's milk that has been detected in the milk of lactating mothers (Cantani et al., 1992).

Biphasic reaction. Any recurrence of allergic symptoms within 1 to 78 hours after the original anaphylactic reaction is resolved (Järvinen et al., 2009; Lee & Greenes, 2000). Biphasic responses can occur in individuals who experienced the initial anaphylactic reaction within minutes of allergen exposure (Tole & Lieberman, 2007). Though biphasic reactions are rare and

unpredictable, they are more likely to occur in people who had a 'delay' in the administration of epinephrine (Järvinen et al., 2008, 2009; Lee & Greenes, 2000; Tole & Lieberman, 2007).

Bronchodilator. A drug that is given to open the airways of an individual who is experiencing an asthma attack (Rosello & Huete, 2015).

Bronchospasm. Narrowing of the airway which makes breathing difficult. For the purposes of my study, bronchospasm can be a life-threatening symptom of anaphylaxis (Garcia-Careaga & Kerner, 2005; Järvinen, 2009).

Cardiovascular collapse. A cardiovascular collapse is a sudden drop in blood pressure which, for the purposes of my study, is a serious symptom of anaphylaxis (Shadick et al, 1999) that can "in the absence of other symptoms . . . represent anaphylaxis" (Canadian Society of Allergy and Clinical Immunology, 2014, p. 3).

Casein. A protein found in the milk of all mammals. As pertaining to my study, casein is the primary protein in cow's milk and has been detected in the breast milk of lactating mothers (Cantani et al., 1992).

Conjunctivitis. For the purposes of my study, an inflammation of the surface of the eye which can be caused by an allergic reaction to pollen or mold (Binkley, 2002).

Contact urticaria. Contact urticaria or hives that occur when a food "though tolerated when eaten" results in a skin reaction when in direct contact (Sicherer, 2013, p. 7). This form of urticaria commonly occurs in infants and children when they consume acidic fruits, such as tomatoes and strawberries (Sicherer, 2013) and has also been described in relation to natural rubber latex (Nutter, 1979).

Corticosteroid. A corticosteroid is an anti-inflammatory drug that is administered via inhaler and is primarily used by people with asthma (Rosello & Huete, 2015). For the purposes of my research, it is important to note that some studies suggest a correlation between the early

administration of corticosteroids and the reduced likelihood of a biphasic anaphylactic reaction occurring in patients who received only epinephrine (Douglas et al., 1994; Järvinen et al., 2009; Tole & Lieberman, 2007).

Cow's milk protein allergy (CMPA). When an individual has an allergic response to the proteins in cow's milk or products that contain cow's milk. With respect to my research, cow's milk protein is the allergen most frequently suspected in fully breast-fed infants who show atopic symptoms (De Boissieu et al., 1997). If the maternal elimination of cow's milk results in an improvement of symptoms in the infant followed by a return of symptoms when the mother ingests cow's milk, this challenge is accepted as indication of a cow's milk protein allergy in the infant (Schach & Haight, 2002).

Cradle cap. Seborrheic dermatitis (SD) or cradle cap is the name for the greasy, yellow, scaly patches of skin that commonly appear on a newborn's scalp before the age of 3 months (Singleton, 1997). The patches usually appear on the scalp but can also spread to the forehead, nose, or ears. The scales can be softened with an emollient such as white petrolatum or mineral oil and eventually the flakes can be gently removed (Singleton, 1997). Cradle cap is difficult to distinguish from atopic eczema in infants (Cant et al., 1985). Both cradle cap and eczema have been known to persist in infants who are eventually diagnosed with food allergies (Warner, 1980).

Cross-contamination. Also known as cross-contact, cross-contamination occurs when a harmful food allergen is contained in an "otherwise allergen-safe food" often as a result of human error during food preparation procedures (Sicherer, 2013, p. 151).

Cross-reactivity. The term cross-reactivity is used to describe the allergic that results when the human body mistakes a food protein for a pollen protein allergen with a similar molecular structure (Binkley, 2002). Pollen proteins that have been identified as related to oral

allergy syndrome include: birch pollen, ragweed, grass, and mugwort (Bahna, 2003a; Sabra et al., 2003; Sicherer, 2013). People who are allergic to birch pollen may experience a crossreactive response to raw: apples, cherries, nectarines, peaches, pears, plums, grapes, apricots, tomatoes, almonds, hazelnuts, carrots, celery, and potatoes (American College of Allergy, Asthma & Immunology, 2014; Bahna, 2003a; Binkley, 2002; Garcia-Careaga & Kerner, 2005; Rosello & Huete, 2015; Sabra et al., 2003; Sicherer, 2013). Individuals who have grass pollen allergy may have reactions when eating banana, kiwi, peach, potato, and tomato (Bahna, 2003a). Ragweed is known to be cross-reactive with bananas, melons, carrots, and celery while mugwort-affected individuals may experience oral allergy syndrome while consuming celery or spices such as fennel, coriander, and parsley (American College of Allergy, Asthma & Immunology, 2014; Bahna, 2003a; Binkley, 2002; Sabra et al., 2003; Sicherer, 2013). The natural proteins in latex can cause people to react to: bananas, kiwi, chestnuts, avocados, mangoes, figs, peaches, tomatoes, potatoes, and bell peppers (Birmingham & Suresh, 1999; Sicherer, 2013).

Diaphoresis. Profuse sweating. As it pertains to my study, diaphoresis can occur during an anaphylactic reaction (Lee & Greenes, 2000).

Dysphagia. Difficulty swallowing. For the purpose of my study, dysphagia is a symptom of food allergy brought on by swelling of the throat or esophagus (Garcia-Careaga & Kerner, 2005).

Eczema. See atopic dermatitis (above).

Eosinophil. An eosinophil is a type of immune system cell that "causes asthma and chronic allergic inflammation (Sicherer, 2013).

Eosinophilic Esophagitis (EoE). A chronic illness triggered by food allergens that causes inflammation in the esophagus making it difficult to swallow food (Sicherer, 2013).

Exercise-induced anaphylaxis (EIA). A chronic but episodic form of physical allergy that begins with fatigue, flushing of the skin, warm pruritus (itchiness), and urticaria (hives) most commonly on the face, hands, and the soles of the feet of susceptible individuals who are engaged in physical activity (Shadick et al., 1999; Sheffer & Austen, 1980).

Exercise-induced asthma. Asthma that "manifests as wheezing associated with vigorous exertion occurring during, or more commonly, after exercise" (Kidd et al., 1983, p. 410).

Firstborn child. For the purpose of my research study, the term "firstborn" child refers to the oldest living child of the biological mother.

Food intolerance. Unlike food allergy, food intolerances do not involve the body's immune system and typically manifest in the gastro-intestinal tract as bloating, gas, or diarrhea (Robinson & Ficca, 2012; Rosello & Huete, 2015; Sicherer, 2013). Two common food intolerances are lactose and gluten whereby affected individuals have difficulty digesting the sugar found in milk (lactose) and protein (gluten) in grains such as wheat, rye, barley, and oats (Rosello & Huete, 2015).

Flushing. When a person's skin (especially the face) becomes hot and red. Flushed skin commonly occurs as a symptom of exercise-induced anaphylaxis (Shadick et al., 1999).

Food-dependent exercise-induced anaphylaxis (FDEIA). Food-dependent exerciseinduced anaphylaxis or FDEIA is a rare, underdiagnosed (Medveczky, 2014), and not well understood (Romano et al., 2012) form of exercise-induced anaphylaxis that is brought on by strenuous exercise (Silverstein et al., 1986). Despite having no reaction to the food, independent of exercise, and no reaction to exercise alone, FDEIA is more likely to be experienced by people with "hypersensitivity" to multiple foods (Romano et al., 2012, p. 1651; see also Medrala et al., 2014; Shadick et al., 1999) and occurs within 2 hours of trigger allergen ingestion (Silverstein et al., 1986).

Gastroesophageal reflux disease (GERD). Gastroesophageal reflux, also known as acid reflux, is caused by acid from the stomach coming up into the esophagus. For the purposes of my study, there seems to exist a link between individuals who have a milk allergy and acid reflux, though reflux is not believed to be caused by food allergies (Sicherer, 2013).

Gliadin. A protein found in wheat gluten which has been detected in the milk of breastfeeding mothers (Cantani et al., 1992).

Helminth. A helminth is a parasitic worm. For the purposes of my study, helminths are believed to have co-evolved in the human body and take on a protective role. The absence of helminths in the body has coincided with an increase in illnesses of the immune system (Rook et al., 2003; see also Elliott et al., 2007; Velasquez-Manoff, 2012).

Hirschsprung's disease. A "congenital intestinal aganglionosis (CIA) a lack of nerve (ganglion) cells in a segment of the bowel" (American Pseudo-obstruction and Hirschsprung's Disease Society, 2000).

Histamine. A histamine is a hormone that is produced by the immune system when an invading allergen is identified by the body. Histamine is involved in the regulation of blood pressure and causes "redness, swelling, and excessive secretions from the skin and mucous membranes" (Rosello & Huete, 2015, p. 15).

Immune system. The body's immune system is made of cells that move through the blood looking for foreign molecules such as bacteria, viruses, or parasites, to safely destroy
(Binkley, 2002; Rosello & Huete, 2015; Sicherer, 2013). For an individual who has allergies, the trigger allergen encourages the immune system to produce antibodies to fight the against the allergen (Canadian Society of Allergy and Clinical Immunology, 2014).

Immunoglobulin. Also known as Ig, immunoglobulins are the antibodies that are produced by the human body to fight bacteria and viruses, the five types being: IgA, IgG, IgM, IgD, and IgE. Often tested together, immunoglobulins A, G, and M (found in the mucous membranes, bodily fluids, and blood/lymph respectively) provide information on infection or autoimmune disorders (KidsHealth, 2015). Immunoglobulin D, though not well understood, is found in the blood and is believed to have immune system activation properties similar to Immunoglobulin M (Chen & Cerutti, 2011). Discovered in 1966, Immunoglobulin E, is most relevant to my study as it is believed to be the immunoglobulin responsible for the majority of allergic and asthmatic reactions (Ishizaka et al., 1966; Rosello & Huete, 2015). High levels of Immunoglobulin G, however, have been found in individuals who have food intolerances indicating the body's attempt to build tolerance to the offending food (Psenka, 2014). Since Immunoglobulin E and Immunoglobulin G reactions can produce similar skin, respiratory, and gastrointestinal manifestations, the cause of symptoms can be difficult to determine without blood tests (Rosello & Huete, 2015).

Immunotherapy. An experimental allergy treatment given under the supervision of a physician to atopic individuals whereby increasing amounts of the offending allergen protein is given to the patient with the intent to increase tolerance and eventually desensitize the person to the allergen (Greenhawt & Vickery, 2015; McGowan & Wood, 2014). As it pertains to my study, oral immunotherapy (OIT) and sublingual immunotherapy (SLIT) are the two most commonly explored food-allergy immunotherapies currently being tested with milk, egg, and

peanut proteins (McGowan & Wood, 2014). Oral immunotherapy involves the ingestion of offending food proteins in powder form or mixed in a food source (McGowan & Wood, 2014). In sublingual immunotherapy, a liquid version of the food protein allergen is held under the tongue for two minutes before being swallowed by the individual (McGowan & Wood, 2014). Immunotherapy injections given to build up tolerance to trigger allergens have been known to cause both serious near-fatal and fatal allergic reactions (Stewart & Lockey, 1992).

Leadership. My understanding of leadership as used in my dissertation refers to the ability to ethically guide others.

Mastocyte. A mastocyte is the type of cell that is responsible for the immediate immune system response that occurs when a person comes in contact with an offending allergen (Rosello & Huete, 2015).

Methylprednisolone. Methylprednisolone is a corticosteroid that may be given via intravenous by a medical professional to reduce the inflammation associated with anaphylaxis (Järvinen et al., 2009).

Munchausen syndrome. A psychiatric disorder whereby the individual "pretends to be sick or gets sick on purpose" in order to receive attention (Bahna & Oldham, 2014, p. 579). Adults who induce illnesses or exaggerate the symptoms of an individual in their care (most often a child but possibly a spouse or elderly person) for the purposes of medical treatment is known as Munchausen Syndrome by Proxy or MSbP (Schreier 2002, 2004). In upwards of 95% of cases, mothers or mother surrogates were identified as the perpetrators (Schreier, 2002, 2004; see also Feldman, Stout, & Inglis, 2002). For the purpose of my research, parents of children who experienced frustrating delays in having their children with multiple food allergies diagnosed were sometimes accused of allergic Munchausen Syndrome by Proxy (Putnam, 2003).

As of 2005, the term Munchausen Syndrome by Proxy has come under scrutiny, and the behaviours previously associated with MSbP are now being referred to as Fabricated or Induced Illness by Carers or FIIC (Fish, Bromfield, & Higgins, 2005).

Nonsteroidal anti-inflammatory drugs (NSAIDs). A group of drugs that include acetylsalicylic acid, ibuprofen, and naproxen which can be used to reduce fever, pain, or inflammation (Gold et al., 2003). A few common over-the-counter brands names available in Canada include: Aspirin®, Motrin®, Advil®, and Aleve®. With respect to my study, the use of non-steroidal anti-inflammatory drugs can amplify or cause anaphylaxis (Gold et al., 2003; Lieberman & Simons, 2015; Medrala et al., 2014; Romano et al., 2012; Sheffer & Austen, 1980).

Oral allergy syndrome (OAS). Also known as pollen-associated food allergy syndrome, oral allergy syndrome (OAS) occurs when an individual who has a respiratory allergy to pollen consumes a raw fruit or vegetable that contains a protein *similar* to the offending pollen protein (Bahna, 2003a; Sabra et al., 2003; Sicherer, 2013). Cooked forms of the offending fruits or vegetables can often be tolerated by individuals who react to the raw form since the protein is altered during heating which prevents the immune system from recognizing the protein as harmful (Sicherer, 2013; see also American College of Allergy, Asthma & Immunology, 2014; Binkley, 2002; Garcia-Careaga & Kerner, 2005). Symptoms of oral allergy syndrome, though rarely severe, usually begin within minutes of consuming the offending food and commonly include: itchy or tingling ears or mouth, tightness or swelling of the throat, and/or blisters on or around the lips, tongue, and/or palate (Sabra et al., 2003; see also Bahna, 2003a; Binkley, 2002; Sicherer, 2013). Severe cases of oral allergy syndrome have reported symptoms of vomiting, diarrhea, asthma, hives, and anaphylactic shock (Canadian Food Inspection Agency, 2008). Symptoms associated with oral allergy syndrome typically increase during the pollen season,

making consumption of offending foods more likely to initiate a reaction at that time of the year (Sicherer, 2013).

Oropharyngeal. Pertaining to the tongue, palate, and throat. For the purpose of my study, oropharyngeal itch can be an associated symptom of oral allergy syndrome or food allergic reaction (Garcia-Careaga & Kerner, 2005; Hernández et al., 2005).

Ovalbumin and ovomucoid. Proteins in egg white. With respect to my study, ovalbumin and ovomucoid proteins have been found in the milk of lactating mothers of children with suspected food allergies (Cant et al., 1985; Cantani et al., 1992; De Boissieu et al., 1997).

Pathognomonic. Signs or symptoms that almost always accompany a particular medical condition and are frequently relied upon by medical professionals to make an accurate diagnosis. With respect to my research study, the lack of any pathognomonic symptoms of food allergy make diagnosing it very complicated (Cruz et al., 2007).

Peanut butter substitutes. For the purposes of my dissertation, a peanut butter substitute is any food spread that attempts to mimic the flavour and texture of peanut butter and can be used in place of a peanut butter product. Three such substitutes include: Nutella® (hazelnut spread), SunButter® (sunflower seed spread), and WOWBUTTER (soy spread).

Phenoxyethanol. For the purpose of my research, phenoxyethanol is a preservative commonly found in vaccines. It has been known to cause "delayed-type hypersensitivity" reactions but does not cause immediate allergic reactions (Wood, 2013, p. 522).

Physical allergy. A physical allergy is any "immediate hypersensitivity reaction to a physical stimulus" (Silverstein et al., 1986, p. 198). Food-dependent exercise-induced anaphylaxis (FDEIA) and exercise-induced anaphylaxis (EIA) are two forms of physical allergy

triggered by exercise. Other causes of physical allergy include: heat, cold, sunlight, water, physical pressure, or emotional stress (Sheffer & Austen, 1980; Silverstein et al., 1986).

Proctocolitis. Observed in infants at any time during the first 6 months of life, proctocolitis manifests as bloody, mucousy stools in otherwise healthy babies (Maloney & Nowak-Wegrzyn, 2007). Proctocolitis is most commonly caused by cow's milk protein allergy, and estimates suggest that 50% of cases are non-IgE-mediated (Maloney & Nowak-Wegrzyn, 2007; see also Garcia-Careaga & Kerner, 2005). Restricted maternal diets for breast-fed babies or non-allergenic formulas for bottle fed infants may resolve symptoms of proctocolitis (Garcia-Careaga & Kerner, 2005).

Pruritis. Severe itching of the skin. For the purposes of my research, pruritis can be associated symptom of allergic or anaphylactic reaction (Shadick et al., 1999).

Radioallergosorbent test (RAST). This medical blood analysis test mixes samples of a patient's blood with suspected allergens to determine concentrations of immunoglobulins E and G (Rosello & Huete, 2015). While the RAST test can confirm if an allergy exists, it does not indicate the "degree of sensitivity" of the allergen (Rosello & Huete, 2015). For my purposes, a RAST test will be referred to as one of the tools physicians use to diagnose a food allergy.

Serum sickness. A term used at the turn of the 20th century to describe the symptoms that often resulted after the administration of *antitoxin* serum for scarlet fever, tetanus, and diphtheria. Symptoms appeared within days or weeks of receipt of the injection and could include: rash, fever, joint pain, swelling, trouble breathing, lowered blood pressure, and sometimes death. For the purpose of my study, serum sickness provides an early picture of allergy and the symptoms that would eventually be named anaphylaxis (Vaughn, 1941).

Skin-prick test (SPT). Performed under the supervision of an allergist, the skin-prick test requires a small amount of suspected allergen serum (or food sample, in the case of suspected food allergies that do not have a prepared serum) on the arm or back of the patient. A new sterile lancet is then used on each sample to break the skin, which allows for the suspected allergen to enter the body (Bindslev-Jensen, 1998; Rosello & Huete, 2015). In addition to the specific allergens being tested, saline and histamine pricks are also done and act as controls (Järvinen et al, 2009; Rosello & Huete, 2015). After approximately 10 minutes, the skin is examined for signs of an allergic response. If hives do appear, the size of the allergic wheal is measured to determine the severity of the reaction. Despite false positives (Rosello & Huete, 2015), the skin-prick test is unlikely to be replaced as it is relatively accessible, easy to use, and it produces immediately visible results (Masse et al., 2011).

Stridor. A high-pitched wheezing sound made when an individual with a blocked airway tries to inhale. Stridor is a sign that the upper respiratory tract is swelling during an anaphylactic episode (Sheffer & Austen, 1980).

Tachycardia. An abnormally fast heart rate, or tachycardia can be a symptom of vascular compromise brought on by anaphylaxis (Shadick et al., 1999).

Thimerosal. As pertaining to my study, thimerosal is a preservative commonly found in vaccines. It has not been known to cause immediate reactions, but has caused "delayed-type hypersensitivity" reactions (Wood, 2013, p. 522).

Tri-Vi-Sol®. A combination of vitamins A, C, and D designed to support growth and immune system development in breast-fed infants (Mead Johnson & Company, 2014).

Urticaria. Also known as hives, urticaria are small, itchy, round, red (or sometimes white) welts that can appear on the upper layers of the skin as a result of an allergic reaction

(Canadian Society of Allergy and Clinical Immunology, 2014). For the purposes of my research, urticaria will be referred to as a symptom of an allergic or anaphylactic reaction and as one of the most frequent symptoms of exercise-induced anaphylaxis (Shadick, et al, 1999).

Vaccine. A small inactive amount of a virus or bacteria that is administered orally, by injection, or inhaled to stimulate the production of antibodies in order to fight future viruses or bacteria that may be encountered (Immunize Canada, 2015). *Vacca* comes from the Latin word for cow; the first vaccine was created using scabs from infected cows (Vaughn, 1941).

Wheal. An itchy, red, swollen mark or hive that may appear on the skin at the site of an allergic response to a serum or food product during a skin prick allergy test. The length and width of the wheal are measured by the allergist to help determine the allergic response, though the wheal size will vary from person to person (Allen et al., 2013; Burks et al., 2012).