Journal of Applied Hermeneutics
ISSN: 1927-4416
August 14, 2024

DOI: 10.55016/ojs/jah.v2024Y2024.79827

When Allergies Take a Backseat: Interpreting the Experiences of Mothers of Teenaged Children with Life-threatening Food Allergies

Karen Dobbin-Williams

Abstract

In this paper, I report on my doctoral study exploring the experiences of mothers of teenagers with life-threatening food allergies. Using the metaphor of a car in motion as mothers navigate this time with their children, I offer some deepened understanding of this topic: going forwards while looking backwards; allergies taking a backseat; and the teenager taking the wheel. Expectations of mothers and the roles that mothers take on are explored in this interpretive inquiry guided by Gadamerian philosophical hermeneutics.

Keywords

Life threatening allergy, anaphylaxis, teenagers, mothers, philosophical hermeneutics

As the mother of a teenager with life-threatening food allergies at the time of my PhD study, I had intimate experience with the topic of being a mother of a child with life-threatening food allergies. However, I was only one of many mothers of over 470,000 Canadian children under the age of 18 years with food allergies (AllerGen, 2020). While I had personal insights into what this experience was like, this topic required further exploration to bring forth the experiences of other mothers who inhabited this topic with me. I offer some deepened understanding I have gained from interviewing mothers and the sharing of their caring experiences as their teenaged children with life-threatening food allergies navigate the teenaged years.

In this paper, I discuss some aspects of my hermeneutic study of this topic undertaken in my PhD studies under the supervision of Dr. Nancy Moules in the Faculty of Nursing at the University of Calgary. For this doctoral study, I interviewed seven mothers, and analyzed the data from these

Corresponding Author:
Karen Dobbin-Williams, RN PhD
Memorial University of Newfoundland
Email: kdobbinw@mun.ca

interviews interpretively. I offer some of these findings here that address the very personal and complex issue of being a mother with a teenaged child with life threatening food allergies.

Background

Globally, the prevalence of food allergies based on self-report ranges from 1% to 10%, and continues to increase (Loh &Tang, 2018; Soller et al., 2012; Tanno et al., 2021). Food allergy is an incurable chronic health condition with immune system hyper-sensitivity responses to specific food proteins, referred to as allergens (Huether et al., 2023). Life-threatening food allergy (LTFA) reactions, known as anaphylaxis, is caused by exposure to allergens. This may cause symptoms ranging in severity from hives, itching, and vomiting, to more serious symptoms, such as low blood pressure, systemic swelling, and difficulty breathing (Huether et al., 2023). Without the life-saving treatment of epinephrine injection, reactions may progress to airway swelling, reduction in oxygen to the lungs and other vital organs, and anaphylactic shock, organ failure, and death (Huether et al., 2023). Emergency room visits for anaphylaxis have increased by 13.2% in Australia (years 1994–2005), doubled in the United Kingdom (years 1998–2012), and increased by 95% in Canada (years 2006–2014) (Canadian Institute for Health Information [CIHI], 2015; Loh & Tang, 2018; Munoz-Furlong & Weiss, 2009; Xu et al, 2014).

Teenagers are more likely to die from anaphylaxis than any other age group in Canadian emergency room (ER) visits (CIHI, 2015; Munoz-Furlong & Weiss, 2009; Xu et al., 2014). ERs saw 23 teenagers per 100,000 total patients in ER for anaphylaxis in 2006/2007 and this more than doubled to 59 teenagers per 100,000 total ER patients for anaphylaxis in 2013/2014 (CIHI, 2015). Youth aged 13-17 years of age experienced the highest increase in anaphylaxis between 2006 and 2014 (CIHI, 2015). The unpredictability of how severe the reaction will be and the timing of the reaction are very stressful for individuals with LTFAs and their loved ones.

“Teenager” is a somewhat colloquial name for what is more formally described as an adolescent. Distinguishing adolescence is more than a simple assignment of a numerical age between 10 and 18; rather it is defined as a developmental period of life, marked by rapid physical, emotional, and cognitive change (World Health Organization, 2009). The term teenager was used in this study to refer to adolescents located in the “teen” years of 13-18 years.

Teenagers with LTFAs have a chronic medical condition with no cure. The only treatment is an injection of epinephrine within seconds of eating the offending food. Those affected face the potential for a deadly reaction each time they eat. It is well documented that having a food allergy is challenging and significantly affects many aspects of a teenager’s and their family’s life (Annunziato et al., 2013; Chow et al., 2015; Moen et al., 2019). This includes negative effects on quality of life (Avery et al., 2003; Drakouli et al., 2023; Knibb et al., 2016; Morou et al., 2014; Sicherer et al., 2001; Wassenberg et al., 2012), worsened stress and anxiety, and increased burden with respect to embarrassment and feelings of deprivation of those with food allergy (Fenton et al., 2011; Gillespie et al., 2007; Golding et al., 2021; Herbert et al., 2016; King et al., 2009; Komulainen, 2010; MacKenzie et al., 2010; Primeau et al., 2000; Saleh-Langenberg et al., 2016; Sommer et al., 2014; Stensgaard et al., 2016; Williams et al., 2009; Wilson-Forrest, 2007). Food allergy is also known to contribute to bullying and social isolation (Akeson et al., 2007; Dunn Galvin et al., 2009; Fenton et al., 2011; Herbert et al., 2016; Lieberman et al., 2010;

MacKenzie et al., 2010; Marklund et al., 2007; Shemesh et al., 2013; Stensgaard et al., 2016; Warren et al., 2017), and increase food and medication costs for families (Minaker et al., 2015; Protudjer et al., 2015).

While teenagers report seeing constant worry on the part of their parents, especially their mothers, as a normal part of their family life because of the food allergies (Dunn Galvin et al., 2009; Fox & Warner, 2017), parents express concerns and worry about the life-stage transitions their teenaged children undergo (Akeson et al., 2007) including potential exposure to food allergens with social and intimate relationships, get-togethers, and parties. With the increased desire for autonomy and independence during the teenaged years, decision making about what food is eaten, where and when to carry the epinephrine, and emergency management should a food allergen exposure occur, may be up to the teenager. For mothers of these teenagers, this time may be fraught with uncertainty, not because of the constant monitoring reminiscent of the childhood years, but because of the transfer of responsibilities for vigilance in care and prevention of reactions from parent to child.

The teenaged years are often considered to be a time of heightened sensitivity of teenagers to fit in with peers with the potential to engage in some risk-taking behavior. The worry and unpredictability associated with LTFAs can be acutely felt by the mothers of these teenaged children. There are very few studies that explore the experiences of mothers of teenagers with LTFAs which makes then a poorly understood population and a group that are in need of specialized support and knowledge.

In summary, there is very little research published about the experiences of mothers of teenagers with LTFAs. While some conjectures may be made on how teenagers experience LTFAs and its influence on their mothers, the experience of mothers is not known. In addition, while qualitative methods used in previous studies such as grounded theory, descriptive phenomenology, and ethnography, perhaps explore the experience more fully than some quantitative measures, the complexity of the experience has not been examined through a hermeneutic lens. Specifically, there has been no interpretive research informed by a Gadamerian philosophical hermeneutic approach done in allergy research. Allergy affects not only individuals with allergies but also their world around them, in particular their mothers, and their families. There is a gap in the literature, a gap in the methodologies used, and the context in which the research has been done. With a hermeneutic inquiry approach guided by Gadamerian philosophical hermeneutics, key components of experience such as language used to describe the experience, culture (particularly around food and social customs), history, and tradition add to the richness of this study. The purpose for undertaking this study was to offer new understandings of how it is to mother a teenager with life-threatening food allergies. The research question was: How might we understand the experiences of mothers of teenagers with life-threatening food allergies?

Research Method and Design

Utilizing interpretive inquiry guided by Gadamerian philosophical hermeneutics, this research study involved “reflective practice” (Davey, 2006, p. 3), where one engages in “the tradition, philosophy, and practice of interpretation” (Moules, 2002, p. 2; Moules et al., 2015). Given that Gadamer was a student of Heidegger, there is a strong emphasis on interpretive phenomenology in this research approach. Gadamer also was influenced by Schleiermacher and Dilthey, and believed in making meaning through conversation, the use of words, and the consideration of context, history, and time (Gadamer, 2001, 2007). To be able to interpret and create new understandings, he felt one had to remain open to new meanings about topics in daily life. With a strong emphasis on language and dialogue (Lawn & Keane, 2011), Gadamer's philosophy is about the understanding of human experience through genuine conversation and the specific language used in the conversation. There is no bracketing aside of assumptions in this tradition as might be seen with the descriptive phenomenology of Husserl. Rather, those engaged in the philosophical hermeneutic tradition bring their prior understandings to the discussion but allow the work of *aletheia* to occur where a portal opens, or there is an enlivening, a remembering of something hidden or forgotten and new meaning occurs (Gadamer, 2007; Moules, 2002; Moules et al., 2015). The goal in hermeneutic inquiry is to seek understanding through interpretation. It is not a quest to represent people's stories as told or to explain phenomena (Moules et al., 2015). Hermeneutics is always about understanding rather than explanation, and about bringing light to the topic (Gadamer, 1960/2013, 2007; Moules et al., 2015).

The study was completed in Newfoundland, Canada, and ethics approval was received from the University of Calgary Conjoint Health Research Ethics Board and the Health Research Ethics Board of Memorial University of Newfoundland. Inclusion criteria was mothers of teenaged children aged 13-18 years old with life-threatening food allergies who spoke English.

Data Collection and Analysis

Seven mothers of teens (age 13-18 years) with LTFAs were interviewed for 1-1.5 hours each. The teens had allergies to milk/dairy, eggs, peanuts, tree nuts, fish, and kiwi. Each interview was audio-recorded, and transcribed verbatim. Interpretive analysis was carried out through repeated immersion in the written text from transcribed interviews and memos/notes written during and after the interview. Data were organized into themes, similarities and differences were noted in an individual interview and across interviews (parts and whole of the hermeneutic circle), and key phrases and words were then studied in literature and research to offer interpretive conjectures. Beginning interpretations were discussed with an expert in interpretation, with an eye to looking for interpretations that were strong, recognizable, convincing, persuasive, and that resonated as "true" of the topic (Moules, 2002).

Interpretive Findings

The interpretive findings from this study revolve around three key interpretations: 1) Looking Backwards While Going Forwards, 2) Allergies Take the Backseat and the Teenager Takes the Wheel, and 3) The Panopticon of Mothers of Teenagers with Life-threatening Food Allergies: Vigilance, Watchfulness, and Surveillance. In this paper, I have chosen to discuss the first two interpretations.

All mothers, when asked about their experiences of mothering their children in the teen years, referred to the early years with their children and the increased mother-work of navigating school trips, birthday parties and family gatherings, and vigilance around ensuring epinephrine was always available, checking long lists of ingredients, and baking and cooking special foods.

Sharing experiences about discovering how their child was diagnosed with LTFAs figured key in the interviews. The imagery of the backseat of a car came up so many times when discussing experiences with mothers.

Looking Backwards While Going Forwards

Hearing the stories of mothers of teenagers with LTFAs and reflection on the similarities of their stories of looking backwards into the past when talking about their experiences, there is the suggestion that when children with LTFAs are younger, the mother is figuratively in the front seat of a car and the car is being driven by her, constantly moving forwards as the child is growing. She maintains control of what the child is eating, where the child goes, and with whom the child interacts as they begin to grow up. She is the driver, navigator, and watchperson of other passengers in the car. The child's LTFAs, reactions, and treatments occupy an important space in the backseat of this figurative car. While the topic of this study was an understanding of the experience of mothering a teenager with LTFAs, this understanding involves both going forwards and backwards, similar to the functions of a car. As the child grows older and matures, that is, forward movement; mothers shared that, as this movement forwards during the teenaged years was occurring, they were always looking backwards on their experiences. The words of mothers are in italics with quotations that support my interpretations.

Looking in the Rearview Mirror

> She charged down the road, foot heavy on the gas, propelling forwards, well over the speed limit, as her heart pounded out of her body. As she came up over the crest of the hill, the scene in front of her were cars everywhere, as far as the eye could see there were cars…stopped, at a standstill. Waving furiously and sounding her horn at everyone in her path she careened around the stopped cars, tears streaming down her face as she viewed the situation unfolding in the backseat. Her five-year-old child - - swollen, barely breathing, limp, and deathly grey in colour. The hospital was only 15 minutes away. She had always driven herself and her child to the hospital in past reactions. Like many other times before, she had given the epinephrine for some accidental food exposure and scooped him up to drive to the hospital. This time was different though; through her limited view into the backseat of the car through the rearview mirror, she could see her child dying. His face was swollen beyond recognition and the sound of his breathing - primal… a low, grinding sound of air trying to pass through the narrowest of openings. The sound of this precious child gasping for air has never left her mind.

This mother recounts:

> *I learned the hard way to call an ambulance to go to the hospital because one of his reactions when he was about 5, I gave him the epinephrine and he was having a very severe reaction that time and I gave him the epinephrine and decided to get in the car and drive myself. I guess I just wasn't thinking and I ended up getting stuck in construction on a major street that we have here and I could see him in the back seat in the rearview mirror and he's getting puffier and puffier and his breathing is getting faster and more difficult and he's getting really distressed and by the time I get him to the hospital he's completely*

> *limp, he was grey, they couldn't get oxygen saturations on him, and he was a full resuscitation.*

As this mother told her story, she thought back as she reflected on the memory of this terrifying time in her life as a mother of a child with LTFAs. Her gratitude that he had survived despite her decision to drive him herself and not being able to proceed forwards to the hospital was palpable. Like this situation unfolding as the mother looked back through the rearview mirror into the backseat of her car, in other interviews with mothers, they too looked back into the past to recall times they had experienced mothering their child with LTFAs. Discussions often focused on looking back into the past when the child was younger. For some mothers, looking back on allergic reactions in the backseat took on a literal meaning because this is where the reactions had occurred.

One mother spoke of her experience of bringing her child in to the ER department when he was in the midst of a reaction almost a decade ago. Her memory of it as fresh as the day it happened:

> *Yeah I'll never forget it and that's 9 years ago now and he's had other reactions since but this one felt really out of control that to the point that, I remember going into the resuscitation room and handing him off and just falling on the floor, literally falling on the floor crying, just I don't know, with the relief I suppose that he was there but really thinking this is the time he's going to die this time… It was like a nurse came in, it was at change of shift and she's like there's a minivan out in the , it wasn't the parking area, it was where the ambulances pull in, she said it's running and the doors are open and she said I took the keys out. I said 'oh my God, that was me'… it was terrible, I'll will never forget looking and seeing him in the rearview mirror.*

Another mother shared a story, as tears streamed down her face, of one of her son's earliest allergic reactions as a baby in a rear-facing car seat in the backseat, so she could not see him but she could hear him:

> *He would've been within a week or two of his first birthday, and he was in a cart in the supermarket with me and he must've put something in his mouth… we didn't know what ingredient caused this because he didn't react right away, (crying) but then I put him in the car seat and we were on the way home and I realized he was having trouble breathing that he was I guess he was having an anaphylactic reaction (crying)… we had no epipen or anything like that and it was a rear facing seat so I couldn't see him. I could hear it and I mean I don't know how I didn't kill both of us that day.*

A third mother spoke of a family trip and trying out a buffet-style restaurant that her husband had checked in advance to ensure that the restaurant was safe in which to eat for their child with LTFAs. Within a few minutes of their 8-year-old son starting to eat, he began to describe his mouth as "spicy," which for this child meant that he was starting to have a reaction. Running out of the restaurant, with no idea of where the hospital was, the mother got in the backseat of the car with her child to give him the epinephrine as he struggled to breathe. As her husband sped along the freeway, she described her fear of searching on her cellular phone for where a hospital might be to bring their child in distress:

> *He actually had an allergic reaction when we were down in Florida one time and that's how I learned to make sure that you always need to know where the hospital is. I was sitting in the backseat with him, I'm giving him the epinephrine and we were looking in our phone trying to Google where the closest hospital was on the freeway… since that time I've always made sure that we're somewhere very close to a hospital.*

Looking backwards and recounting stories of allergic reactions of their children, another mother reflected on her life as a mother of a child with LTFAs and shared the experience of her child having a reaction as a baby in a dimly lit restaurant. She came to the cruel realization when exposed to the bright light of a washroom in the restaurant that there was something seriously wrong with her child before she even knew that her child had food allergies:

> *At the restaurant he'd had a couple of little pieces of the egg, a couple of tiny pieces and I looked at him and said does he look blotchy to you? It was really dark right. I took him into the bathroom and he was covered! and he was (mother is making stridor sound), so we left money on the table and said our son is having some kind of an allergic reaction, we ran straight to the hospital and they figured at the time that it was the egg, because it was the only thing different that had been introduced to the diet and it happened right afterwards.*

There's a Peanut on the Trail! Advocacy of Mothers for their Children

The concept of looking backwards was also threaded through conversations when mothers talked about their experiences that were allergy related, and centered on times mothers had to advocate for their young children or had near misses with allergic reactions. School field trips seemed to be a common challenging issue in which mothers felt they were required to use their advocacy skills.

One mother told a story about how her 11-year-old child's grade five class was planning an overnight field trip at a nature education center in the woods. Told by his teacher that he could not go because of his allergy to peanuts and desperately disappointed about this, this mother was compelled to go to the highest levels of education administration in the province to advocate for her child so that he could experience this exciting adventure with his peers. Her conversation went like this:

> *He came home from school one day and was quite upset and said, "Mom I can't go to Brother Brennan," and I said, "what do you mean you can't go?" and he said, "the teacher said because I have allergies I can't go" So I wasn't going to have that! (laughs) I went in to speak with the teacher and the teacher said, "you're going to have to take that up with the principal," so I went and spoke with the principal and the vice-principal and they said, "it is out of our hands, this comes from higher above," and I said, "well who do I need to speak to?" So it was someone with the school board…, So I went in and he said, "well you know we can't take responsibility for these children up at Brother Brennan, you know they are far away from the hospital and if you were to call an ambulance it's going to take three quarters of an hour for an ambulance and then three quar-*

> *ters of an hour to get them to the hospital." So I said, "ok then, is the food peanut free?" and he said, "yes all the food is peanut free," so I said, "ok, the food is peanut free and I can send food with him like snacks that are peanut free," and he said, "well I can't be responsible, you know, I've told the children not to bring anything, but they might bring something and he might eat it." I said, "well you know he's 11 and he's had his allergies for 11 years and he's not going to eat anything like that"... So the best line was, "well what about if they are taking a walk on the trail and there is a peanut on the trail and he decides to pick it up and eat it?" (Laughing) It's the funniest thing ever! I know I looked at him and I said, "are you serious? Did you just ask me that question?"... Well number one, how is there going to be one up there? And of all things, he's going to say, "I know I'm allergic to peanuts," and I know he's going to say, "oh, look there's a peanut there on the trail that everyone has been walking over that looks so delicious" and he's going to pick it up and eat it, like seriously. I think he realized from my reaction how ludicrous that was.*

Mothers also felt an obligation to go on field trips to allow their children to participate in school activities. One mother shared how she felt an obligation to go on every school field trip with her child so he would not miss out on anything and changed her work schedule and daily life to accommodate this:

> *I always felt like I needed to go you know. Like what if something happened and I wasn't there. I know the teacher knew how to deal with it but they would always ask me if I was coming and I felt like I didn't want to say no.*

Another mother decided that if her child needed her to be there as a chaperone to travel, she would be there while still trying to maintain a low profile so her son would not feel any different than the other children:

> *When they had their school trip to Saint Pierre [An island part of France off the south coast of Newfoundland], they weren't going to fight me on that one, there was some question on if he should go because he had allergies so I volunteered to go as a chaperone to make sure he could have this experience.*

The importance of advocacy in starting school in kindergarten was spoken about by two mothers. In one case, a mother wanted many accommodations made:

> *He started school and it was myself and another lady who her child also had a peanut allergy in the school... we really advocated in the school because the school wasn't peanut free so we went in and spoke with the school, "you know this is for our child a life and death situation, for your child it's sorry you can't have peanut butter before you go to school or you can't take a peanut butter sandwich." My child it's life and death. So you know there was some resistance because it was still fairly new but the school did become peanut free.*

The second mother who advocated for fewer accommodations said:

> *When he started school, I had to meet with the kindergarten teacher in August before school started. She (the teacher) was so nervous because he was allergic to so much then. The principal came in to talk to us and said we are going to make the whole school dairy free and I said no way, the other parents will revolt!*

Mothers have long been known as advocates for their children as are these mothers of children with LTFAs. Almost a century and a half ago in 1870 in Boston, the original Mother's Day was begun because of advocacy on the part of a mother (The Peace Alliance, 2018). Julia Ward Howe was this mother and she was devastated by the suffering and loss of sons and husbands fighting on both sides during the American Civil War. A feminist and believer in the abolition of slavery, she advocated for a day of peace for mothers from all nationalities to come together to talk about peace in the world with what has been called the Mother's Day Proclamation. Part of it reads as follows:

> Arise, then… women of this day! Arise, all women who have hearts, whether our baptism be that of water or of tears! Say firmly: We will not have great questions decided by irrelevant agencies. Our husbands shall not come to us, reeking with carnage, for caresses and applause. Our sons shall not be taken from us to unlearn all that we have been able to teach them of charity, mercy and patience. We, women of one country, will be too tender of those of another country to allow our sons to be trained to injure theirs. From the bosom of the devastated earth a voice goes up with our own. It says: Disarm, Disarm! ~ Julia Ward Howe

The words of this proclamation above still ring true today as mothers continue to advocate for both their own and others' children. The word advocate means to "speak or write in favor of" (Dictionary.com, n.d.). Mothers Against Drunk Driving (MADD) is one such example of this advocacy work for all children began by a mother who tragically lost her own child in 1980. Candice Lightner, mother to 14-year-old daughter Cari, began her advocacy work to raise awareness about the issues of drunk driving as the result of a drunk driving accident that saw her daughter killed by a four-time repeat drunk driver (MADD, 2024). Lightner's advocacy was no longer for her own child but extended to all children and MADD has now become an advocacy group easily recognized by the "Tie One On" red ribbons and mothers speaking out about issues related to drunk driving (MADD, 2024). While not always welcome or permitted to be part of political processes, feminist theorist, Miller (2010), purported that mothers have always been afforded involvement in the political process through advocacy and activism in their attempts to effect change in causes that have social currency. She asserted that it is the innate ethic of care that mothers possess that directs such advocacy and leads many initiatives that selflessly work for the common good of society (Miller, 2010).

This ethic of care and advocacy has expanded to the food allergy world. There are now countless blogs, websites, chat rooms, Facebook sites, X (formerly known as Twitter) accounts, and non-profit organizations, to name a few, that were started by and are run by mothers advocating for children with life-threatening food allergies (Allergy Foodie, 2024; Food Allergy Canada, 2024a; Food Allergy Canada (X - Twitter), 2024b; Food Allergy Research and Education [FARE], 2024). Mothers have led the way with legislation and awareness for safe food handling in schools, availability of epinephrine, and anti-bullying campaigns for those with food allergies

(Department of Education and Early Childhood Development, 2015; Food Allergy Canada, 2024c; Ontario Ministry of Education, 2005). A specific example of this allergy advocacy work in Canada is the work that has been done by Sara Shannon, the mother of 13-year-old Sabrina Shannon. Sabrina had a life-threatening allergy to dairy products, and was a food allergy advocate long before allergies saw their dramatic rise in incidence and prevalence that has been seen this last decade. In 2003, Sabrina innocently consumed french fries in her high school cafeteria that she was told were safe for her to eat and died very shortly after. Her death led to legislation in Ontario that all children are to have anaphylaxis plans in school, aptly named Sabrina's Law; an initiative that has taken hold and spread across the country (Food Allergy Canada, 2024d; Ontario Ministry of Education, 2005).

Don't Eat the French Fries!

Having a near miss with an allergic reaction came through when mothers reflected back on their experiences mothering a child with LTFAs. A mother of a son with a peanut allergy shared a story of a time they were in Florida at an outdoor outlet shopping area when they decided to stop at a food court for a quick bite to eat and her feeling of catching him just in time:

> *I did get caught in Florida a couple of years ago, shopping at one of the big outlet stores at the food court and we went to Chick-Fil-A. I never even thought to ask, so I got the chicken nuggets and fries and we went down and sat down and my son said "did you ask if they, what kind of oil they use" because we always ask where ever we go, any restaurant and I said, "oh N it's just french fries and chicken nuggets, I'm sure its fine." I said, "I'll go check," because you know, I'm not setting a very good example so I went up and I asked the girl I said, "so what kind of oil do you use here, my son has an allergy," and she said "uhhh, just vegetable oil." I said, "you don't seem very confident, are you sure?" and then she stood back and she was looking at the sign where they list all their products and I said "why are you looking up there" and then so I looked at the sign with her and it said 100% peanut oil! Well, my heart stopped I started racing through the food court, waving my hands frantically at my son yelling out "don't eat the french fries" (laughing) so the kids still laugh at that because I was like a maniac there but I couldn't believe it!...that this day and age, a restaurant would use peanut oil. I was shocked anyway, so that time if I hadn't of asked… yep he would've went into anaphylactic shock which would not have been a good place to be in a busy food court in a different country where we don't even know if 911 works or whatever. So that was the most frightening experience I've ever had because it was that close.*

Protection of children by mothers has been discussed over many centuries in many contexts. In the Merriam-Webster dictionary (n.d.), the verb "mother" literally means "to care for or to protect like a mother." Ancient stories in the Old Testament of the Bible tell about the baby Moses being protected from the Pharaoh of Egypt and his plan to kill all male babies, by his mother by putting him in a basket made with bulrushes and sending him down the river only to be found by the Pharaoh's daughter who then raises him as her own thus taking over this child's protection. In present day, mothers' protection mechanism has been linked biologically to the hormone oxytocin (Ayre, 2017) and brain wave patterns on a magnetic resonance imaging (Parker-Pope, 2008). Some describe this protection mechanism as instinctual (Daniel, 2017), while others critique that it is an expectation in society that mothers be good, protective mothers - known as the "good mother myth" (O'Reilly, 2007). In some health-related literature on the role of mothers in caring for children with diabetes and asthma, mothers have been called "alert assistants." In this role they protect their children by absorbing the child's emotions and help their child pass as totally healthy by helping to conceal the illness from others (Williams, 2000). Eventually though, these children grow up and the mothers must begin to let go.

When Car Seats are Long Gone: Junior High School

Mothers of teenagers with LTFAs also reflected back on and shared their concerns about when their children were moving forwards into junior high school and the perceived decreased control over the food allergy:

> *... when he first went to junior high school I was petrified because I knew that he wouldn't be eating in his classroom and people would be walking around eating wherever… there's just less control, you don't have one teacher, there's multiple teachers and who'd be looking out for him and would there be all kinds of pressure? I think the elementary was safer than junior high, ... it's not fair because you know, you have teachers handing out little candies and treats for when you got the right answer and they're tossing treats to the kids. There was an ice cream day ... I didn't know if it was peanut free, I couldn't trust that the kids would do it or if there was a teacher managing the kids to make sure they bought Chapman's [peanut-free] ice cream. So I think there's less support at the junior high. It was a lot of anxiety… the food allergies for us and a lot of counselling him, all of a sudden, he's allowed out at lunch time and be able to go to a restaurant and he's able to order his own food without sometimes telling them that he has a food allergy.*

When their children entered into junior high school, these mothers came to the realization that, while they were still holding on to their children, they were also letting go. As with the interpretation of mothers of teenagers with life-threatening food allergies looking backwards while moving forwards using the metaphor of driving a car, mothers also reflect on the present time and the future of their child with a focus on letting go as the teenagers now takes the wheel of the figurative car and the allergies move to the backseat.

As their children grew older, the mothers indicated that they had to learn to let go of the vigilance they had maintained for their children in the early years and trust that what they had taught their children in the early years about checking ingredients, and carrying their epinephrine, and injecting their epinephrine in a reaction would be done by their children. Junior high school was a key transition point for mothers due to their children's need for increased autonomy and independence, but also due to worries about increased risk taking by the teenagers and less supervision by teachers and more responsibility for the epinephrine in a junior high school setting.

When mothers were asked what they most worried about for their teenaged children, they indicated that they were less worried about the allergies but instead focused on the concerns common to mothers of most teens such as their child fitting in and having friends, doing well in school, having good psychological health, and planning for the future. The LTFAs had almost become normalized for these mothers and had taken a backseat to other worries, and the teenager takes the wheel.

As Allergies Take the Backseat and the Teenager Takes the Wheel

It is quite common in discussion to hear mothers comment on their teenagers and some worries they have about them as they are going through the teenage years. According to Family Systems Nursing theorists, Wright and Leahey (2013), as the teenaged child asserts their independence and desire for increased autonomy, some issues may arise. These issues could include conflicting values, peer pressure, evolving sexuality and intimate relationships, and the potential use of recreational drugs and alcohol (Wright & Leahey, 2013). For the mother of a teenager with LTFAs, I offer that it seemed as though some of these worries had been given some consideration by the mothers in this study as they likely would by most mothers of teenagers, but they existed in relation to the LTFAs, and were not often considered outside the context of the allergies. That is, allergies continued to occupy a space alongside the other worries and concerns.

When discussing mother's current experiences with mothering their teenager with LTFAs, the symbolic interpretation of a location for teenagers with LTFAs and for the mothers of these teenagers in a car still existed but began to shift gears. Allergies now existed in the very crowded figurative backseat – alongside the mother herself and her other worries. While the mother occupied space in the backseat with her concerns about allergies, the teenager took up the space at the driver's wheel in the front as they became more independent. What I interpreted from this was that mothers were telling me that the LTFAs were no longer the most prominent of their concerns though they exerted influence on all their other concerns, so they were never forgotten. Other concerns in the teenaged years now shared space with the LTFAs. Mothers were trying to give their teenaged children with LTFAs some independence in the front to begin to drive the figurative car, as they moved to the backseat.

The phrase, "take a back seat" can mean to take an inferior position, or to allow another to be in control according to the Farlex Dictionary of Idioms (n.d.). This inferior position that food allergies and the mother herself were now occupying, in addition to the mother beginning to allow the teenaged child to take some control, fits with the meaning of this phrase "take a backseat." At one point in an interview, a mother was asked, "At this point in your life are you more worried about the food allergies or the social development of your child?" The mother, seemingly surprised by her own answer, replied, *"I'm more worried about the social development."* While the LTFAs were influential on the mothers concerns overall, they were not their only concern. Continuing in the play with words and moving back, it also became clear that as the allergies and other concerns of the mother, and the mother herself, moved to the backseat of the car, so too did the life-saving epinephrine move backwards.

The Epinephrine Moves Back Too

Epinephrine has a very important place in the lives of individuals with LTFAs. When mothers were asked about epinephrine and their teenaged children, something that stood out was the discussion of the epinephrine moving back too – sometimes to the back of the teenager's mind, sometimes back to the house, and sometimes to the backpack. Mothers shared how they struggled with giving the teenager independence while continuing to remind them to carry their life-saving epinephrine autoinjectors. For one mother, she felt that her son was embarrassed about carrying his epinephrine:

> *My thing, there's always an epipen. He has an epipen which he has in a pouch which he should be wearing but I've noticed in recent months he's wearing it less than he used to, I think he's embarrassed of it - never did before.*

For other parents, they noticed that even though carrying the epinephrine was something that had been reinforced to the child from a very early age, the epinephrine was not always going everywhere with their children and for the father who is a high school teacher in this next example, the school was not asking for the epinephrine either:

> *Mother: He said I'm putting my epipen in my backpack, my friends know it's in my backpack and that's all. Mother: he stopped taking it in junior high, he has it in his backpack and there's one at the office and his home room teacher has one too I think they asked for one. Father: I find in senior high kids don't tell the administration too much about it anymore…there's 10 or 20 kids with some kind of anaphylaxis reaction risk and I don't see 10 or 20 epipens in the office, I see 3 or 4. Mother: I do have to remind him to carry the epipen every morning before he goes out the door or if he's going out with his friends I'm asking him, "have you got your epipen?" I do constantly remind him, but I'm not like, "don't eat anything you're not allowed to eat," I don't have to say that, because I know he won't.*

Another mother shared how her son was now asking if he still needed to carry his epinephrine and if he could leave it back home:

> *No, he puts it on the end of his bedside. We've had a couple of times where he said that he forgot it, so I bring it down to the school not very often though does he forget his epipen. I would say that has happened twice in his probably lifetime. But what we experienced this weekend is "do I have to wear my epipen?"*

For another mother, she indicated that while she valued her child carrying epinephrine, she trusted that if he had the epinephrine with him that his friends would take care of his allergies. Interestingly with the play of the word *back*, this mother talked about not holding her child back:

> *And you know I would have never have held him back from anything because of an allergy. Never. Now, you know, I think I was more worried about his asthma than I was the allergy because I knew his friends would look after the allergy, do you know what I mean? I knew that they'd know what to do.*

One mother indicated that she had made peace with him not bringing his epinephrine if he was not going to eat if that is what her child wanted:

> *I guess too that he's trusting his instincts more, I think he's kind of thinking I'd rather not eat something at my friend's house and not have to worry about bringing an epipen, then I'll take the epipen and I can eat what I want, you know what I mean? I think he'd rather not take it and not eat.*

Other concerns mothers had for their teenaged children centered around if their teenaged child was fitting in and had support from friends, and if mental health issues such as anxiety were arising in their teenaged children. Additionally, mothers' views changed as their children grew older, similar to how the view of a passenger in a car changes, when they move from the front seat to the back seat, and they voiced worries about their teenaged children's feelings of invincibility, their children's independent travel, and also the future of their teenaged children when they moved away from home, completely independent of the mother. When comparing this again to driving in a car, just as our roles change whether we are in the front or back seat of the car, or we are the driver versus the passenger, so do our roles change as mothers as our children grow up and assert their independence.

Fitting In and Making Allergies Fit Alongside Life

A common concern that mothers spoke about was their concern for their children, either or both as a young child and/or as a teenager, regarding having friends and fitting in with the peer group. One mother shared how her child was more sensitive about how he could be perceived as different with the following phrase: *I think it's about being a bit more sensitive about being different and about what people think.*

Another mother of a teenaged son with multiple food allergies shared some of the ways that she tried to make sure he is included in whatever activities he could be with his friends, which did not include her being there, and her irritation when others were not thoughtful of his dietary needs:

> *I always have everything packed.…I always over pack it so that if you got something that you want to choose from, everything is there. So when he goes to the boys houses to play he might be the one to bring the plain chips …And here's a pack of Oreos, so you can have Oreos while everybody else has cake. Sometimes I get a little upset when like the school is having something and they haven't informed me it always bugged me when classrooms had something and I wasn't informed, parents would bring it something for a birthday, birthday cake and nobody informed me.*

Another mother talked about her teenaged child wanting to fit in but still feeling left out due to his allergies and the places he could eat:

> *I know he feels left out sometimes. Like say they'll go for Chinese food or they'll order pizza and some will have a cake you know or whatever, and I think he feels left out then. Now though, they might be like downtown and they might say "let's just pop into this coffee place" and you know he's like "okay," but he can't eat the dessert or the treats or whatever…but you know if they decide they're going for pizza he's sort of like "yeah I'd like to go but I can't eat anything there," but he'll still want to go.*

Another mother when talking about all the extra mother-work she undertook so her son could fit in with his peer group summed it up like this: *It is challenging but to me it's worth the time, it's worth the effort, because everyone feels included and everyone can eat whatever.*

Despite all the efforts the mothers made with helping their child to fit in, sometimes allergies got in the way of this. One mother shared the sadness she felt about her 14-year-old son, having found a group of peers, being prevented from spending time with them due to a serious allergic reaction:

> *The only time I've seen him be very upset is when he had his pistachio [reaction] in the hospital and there was an improv [improvisational acting] competition that he couldn't go to ... And he cried and then he actually had a huge meltdown… I've never seen him cry over his allergies. That night, I actually cried with him because he was mad. He was mad that he was different, he was mad that he couldn't go, he called allergies stupid, he just couldn't get over it.*

Part of the teenaged experience for many teenagers and fitting in is getting a part-time job, often at a fast-food restaurant. However, for children with LTFAs, this may not always be possible. The notion of a teenager having a choice to pursue this is interesting when it relates to allergies. One mother recalled the disappointment her 15-year-old child felt when he had to quit his job at a food establishment because he had already had two allergic reactions when serving food while at work. With the second reaction at work necessitating a trip to the ER after taking his epinephrine, the doctor casually said in reference to the boy deciding to submit his notice of leaving the job, "I'm glad you came to that conclusion," not necessarily recognizing that for the boy, this job was a social outlet and a way to fit in and make new friends as well.

The worries mothers had about their teenaged children with life-threatening food allergies with respect to fitting in and having friends, evolved for some mothers into worries about their child's mental health and well-being.

When It Is Not Just the Allergy to Worry About

Worries about the mental health of their children appeared as a concern for mothers when they reflected back about the allergy experience. One mother of a teenaged son with several food allergies shared her concern about her son's mental health as a young child and subsequently as a teenager while speculating whether some of his mental health issues were related to allergies:

> *From early on, my son has had a lot of issues with anxiety, and you know even as a kid, his heart would be racing at night, he wouldn't be able to sleep and his heart would just be beating out of his chest. I think the allergy did play a role and he was worried about that. He actually went into quite a severe depression. I didn't realize he was in such a deep depression, but it was initially for the allergy and just dealing with this new allergy on top of the other one. So, you know he's been really struggling with the depression for about over a year now but finally we have him, he's taking medication and stuff like that, and we went to a dietitian and stuff but I just wish, I really do believe that there should be*

> *service linked to this immediately you know for families and for children once they're diagnosed.*

Mothers shared how they had been anxious about their child's allergies when the children were younger and were now concerned that their teenaged children were modeling anxious behaviors like the mothers had and if they had somehow passed this anxiety on to their children:

> *… Sometimes you have to kind of pull back a little bit because sometimes I don't know if I'm making him too nervous, too anxious, …I don't know if that is because I put so much worry into everything and then you just sometimes got to think, okay I don't want to make him this paranoid. Or become the opposite and say I'm done with this, forget it, I am done. I am being a normal child. Like you don't want to pass on your anxieties to your child. And sometimes you don't know is it testosterone, is it teenage angst, is it their personality or have you passed on some of your anxiety to your child?…We spend a lot of time trying to make everything right for our children and when something is not going right such as these allergies or depression or anxiety or whatever it might be, I think we do sort of look and ask, "what did I do wrong?" like was it because I was anxious that they're anxious? We blame ourselves and we are always searching, we have that guilt as mothers.*

Mother-blame and mother-guilt, as illustrated in the previous quotes by study participants, are well written about in maternal theory. Mothers are theorized to feel responsible for how their children turn out (O'Reilly, 2007; Ruddick, 2007), and feel blamed when things do not turn out well as judged by society (Blum, 2007; Jennrich, 2010; Ladd-Taylor, 2007; Singh, 2004). Caplan (2007) theorized that mother-blame uses mothers as scapegoats with mothers left feeling guilty about their functioning as mothers if they do not live up to the good mother ideals expected by society (Caplan, 2007; O'Reilly, 2007; Thurer, 2007).

Invincibility and Those Gummy Bears and Shooters

Most mothers worry about their teenagers consuming nutritious food and not consuming alcohol or drugs. The mothers in this study were no exception, but always looming in the background were the LTFAs. One mother shared her distress in hearing that her teenaged son was going to a restaurant and his perceived invincibility while not carrying his epipen:

> *Honestly I feel there's less control now. Like he was a really good child for that - he would actually not eat anything, he'd always ask "is there peanuts in this?" Now, I feel that I have less control now, because as a teenager he feels he's invincible. And he goes off without his epipen and I know a few weeks ago he was going out to restaurant and I dropped him off and I'm like "do you have your epipen?" and he's like "ahh no." So I went home and I'm like "God please bring him back to me" … I mean we were just very diligent to, as a younger child to tell people, make people aware and he was really good, like he was super good. I mean almost to like he wouldn't eat even if they said no, he would be wary. He would not always eat stuff because he would be afraid.*

Another mother shared how she had found out from her teenaged son that he had eaten gummy bears from a bulk food store that commonly has many cross-contamination of allergens that had not been approved by her, and her concern about him doing this. I remember watching this mother as the look of worry came over her face as she likely pondered what other dangers, he might expose himself to: *Well the only thing for me was that the candy, he would never eat anything without passing it by us before and then he did eat those gummy bears.* Drinking alcohol also came up in the concerns mothers had for their teenaged children with LTFA:

> *Kids go out sometimes to go out to a party and you have a few drinks and I said to him, you are not going to be able to drink to the point of getting drunk. I said, "what if you are drunk and one of your friends gives you this shooter and says here, I just bought this for you and you're so drunk that you go ah, okay," I said, "it happens and then you end up on the floor somewhere and somebody thinks you're passed out because you're drunk because it's funny and they don't know that you've just had an anaphylactic reaction." I said, "that scares me to death."*

Worries for mothers not only centered around eating and consuming alcohol, but also letting go to allow their children to travel or go away to school.

When Your Heart is Running Outside of You

Mothers indicated they had concerns about their teenaged children travelling on their own with choirs, for camp, or going away for university or work terms. Some mothers indicated they could not bring themselves to let their teenaged child go or if they did let them go, the mother would have to be very close to where the child was in case they were needed. Some spoke of the fear they felt in letting their child move away. In this next exchange, the pain the mother felt in letting her child go was evident and for the mother could not be captured by words:

> *It was his first time out of the province or out of the country without his parents.* The interviewer asked: *And did that take a lot of courage to let him go?* And the mother responded: *[nodding yes, silence, crying]*

The silence of the mother's answer spoke volumes of what she had felt letting her only son go away to Europe for a trip on his own with his choir. For a music camp close to his home, she also felt scared to let him go*:*

> *That's the kind of scary thing too like how far you are from the hospital like that's what concerned me first at music camp, I remember. If he does have a reaction. You know how many, he has to have enough epipens but you can only use three isn't it?*

One mother shared her struggle with letting her teenaged son go to a camp an hour away from home by himself. She spoke of altering her family's vacation plans so that she could be available when he went to the camp because of her worries about his independent travel and then her frustration with him asserting his independence:

> *Over the summer they have to go to this 2-night 3-day camp, I mean it's only an hour away, I nearly had a breakdown about him going to that… I came back early from a family trip so that I could get him ready to go to this camp but he wouldn't bring the food with him, he's like, "no they told me, everything's going to be fine," and I got mad then, I was like, "fine go." I had left my husband and other two boys up in Toronto so I could come back for him to go to this camp… and then they say that they're going to Cuba and I'm thinking, Cuba is still very far behind the times even though some of the resorts are nice, a different language, first time away from home, away from his parents, I mean I was nearly beside myself… I mean, I was just in a panic about it.*

Mothers also spoke of concerns that they have about their children moving away or going away for school.

> *He does talk about wanting to go away to McGill to do a master's degree and he does talk about when he finishes high school you know, he wants to travel for a while and it frightens the life out of me to be honest with you, it's nerve wracking for me to think about it. So I try not to think about it (laughs), I try to avoid it. I don't want him to move, (crying)*

In sharing with my supervisor of these concerns of mothers about their children with LTFAs travelling on their own or moving away, she was reminded of the song "Delivered" by country artist, Karla Anderson. The phrase that stood out so clearly was: "*It's the kind of love you can't walk away from though you watch it walk away from you. Like your heart's running around outside yourself and there's nothing you can do except let it go and somehow keep it safe and let it grow and feel it ache…it's a painful beautiful love."* Mothers give a part of their hearts to their children and the child becomes an extension of them. As the child is trying to find their way in the world, the mother feels pain as she worries about all kinds of unknowns – friendships, school, health, happiness, safety, partners, work, and their future. I believe that most mothers would say that raising their children to be independent adults who are well adjusted and feel loved are important goals, while they still may struggle with letting go. For the mother of a child with LTFAs, I wonder if this letting go and allowing room for independence is felt even more acutely as they transfer responsibility for the allergies and keep watch at a distance.

Implications

Prior to this study, there were no studies about the experiences of mothers of teenaged children with LTFAs from a philosophical hermeneutic perspective. By conducting this research, there is new knowledge in this field and a gap has been addressed. The catharsis the mothers experienced by sharing their experience with someone who understood and has "been there" with a teenager with LTFAs appeared to be beneficial to the mothers. By these mothers being selfless and honestly sharing how they were experiencing life, this could inform how other mothers may be supported. At the end of each interview the mother was asked to share three "nuggets" of information that they would want to give to a mother of a child who has just been diagnosed with a LTFA. The mothers very rarely focused on their needs but instead focused on how their children's lives could be better through the mother's efforts. This was, in many ways, a fascinating observation that somewhat mirrored the roles and positions the mothers had taken in this experience - - making their children's lives better rather than concern for themselves.

Mothers spoke about how they would recommend that mothers of children with LTFAs who were newly diagnosed should become an advocate for their child until the child could advocate for themselves. In carrying out this advocacy work, mothers emphasized the importance of constantly updating their knowledge and educating themselves through questioning, readings, and research. The importance of teaching children to carry their epinephrine auto-injectors was also identified as important, and giving their children freedom and independence, while putting trust in them that they would make good decisions related to their allergies. The importance of mothers in controlling their own anxiety about the food allergies was also highlighted, so that the anxiety did not get passed on to the child. This came with the caveat that children should be taught to be careful and vigilant about their food allergies, but not let it take over their life. Mothers also suggested support services for the children and family members, with support of the whole person - from specialists, nurses, counselors, dietitians, social workers, and peer support groups.

Conclusion

From this study, the one, true, ultimate answer in how to support each and every mother as she goes through this experience has not been found, and the experience of caring for a teenager with LTFAs cannot be reduced to a single experience. This research study offers a glimpse into the experience of mothers of teenagers with LTFAs. There are some similarities in the experience for mothers as elucidated in this manuscript and it is clear that supports are necessary to decrease the feelings of loneliness and isolation in being the only advocate for their child. The role of registered nurses in allergy care and support has not been explored in any depth in published studies and this requires further research. Further research is also needed in this area as teenagers become adults and become more independent and the influences this has on not only themselves, but also their mothers and family of origin as they move on with their lives.

Acknowledgement

Meeting Dr. Nancy Moules in 2011 changed the course of my PhD, teaching career, and nursing practice. I learned what it was to be a steadfast mentor to students and to be their ally when needed. Being introduced to Gadamerian philosophical hermeneutics, and the intersection of creative, meaningful writing with robust research through conversation with others on the trajectory of their lives, changed the way I look at things. Thank you for sharing this incredible worldview with me Nancy and allowing the work of aletheia to be part of my life.

References

Advocate. (n.d.). In *Dictionary.com*. Retrieved from
https://www.dictionary.com/browse/advocate

Akeson, N., Worth, A., & Sheikh, A. (2007). The psychosocial impact of anaphylaxis on young people and their parents. *Clinical and Experimental Allergy, 37*, 1213-1220.

https://doi.org/10.1111/j.1365-2222.2007.02758.x

AllerGen. (2020). *Estimated food allergy prevalence among Canadian children and adults.* Retrieved from https://www.canada.ca/en/health-canada/services/food-nutrition/food-safety/food-allergies-intolerances/food-allergen-research-program/research-related-prevalence-food-allergies-intolerances.html

Allergy Foodie. (2024). *Allergy Foodie Blog*. Retrieved from https://allergyfoodie.org/

Annunziato, R., Shemesh, E., Weiss, C., Izzo, G., D'Urso, C., & Sicherer, S. (2012). An assessment of the mental health care needs and utilization by families of children with a food allergy. *Journal of Health Psychology, 18*(11), 1456-1464. https://doi.org/10.1177/1359105312464675.

Avery, N., King, R., Knight, S., & Hourihane, J. (2003). Quality of life in children with peanut allergy. *Journal of Allergy and Clinical Immunology, 111*(2), S194. https://doi.org/10.1016/S0091-6749(03)80662-0

Ayre, M. (2017). *The secret behind your mama bear instinct*. Retrieved from https://honey.nine.com.au/parenting/science-discovers-how-mothers-protective-instinct-works-when-children-threatened/8105c445-26d5-4b61-8890-720732a97de8

Blum, L. (2007). Mother-blame in the Prozac nation: Raising kids with invisible disabilities. *Gender and Society, 21*(2), 202-226. https://doi.org/10.1177/0891243206298178

Canadian Institute for Health Information (CIHI). (2015). *Anaphylaxis and severe allergy in the emergency department data tables*. Retrieved from https://www.cihi.ca/en/anaphylaxis-and-allergy-in-the-emergency-department

Caplan, P. (2007). Don't blame mother: Then and now. In A. O'Reilly (Ed.), *Maternal theory: Essential readings* (pp. 592-600). Demeter Press.

Chow, C., Pincus, D., & Comer, J. (2015). Pediatric food allergies and psychosocial functioning: Examining the potential moderating roles of maternal distress and overprotection. *Journal of Pediatric Psychology, 40*(10), 1065-1074. https://doi.org/10.1093/jpepsy/jsv058

Daniel, S. (2017). *A mother's instinct – Moms just know.* Retrieved from: https://www.professorshouse.com/a-mothers-instinct/

Davey, N. (2006). *Unquiet understanding: Gadamer`s philosophical hermeneutics*. State University of New York Press.

Department of Education and Early Childhood Development Government of Newfoundland and Labrador. (2015). *Guidelines for anaphylaxis management in schools*. Retrieved from: https://www.gov.nl.ca/education/files/k12_studentsupportservices_anaphylaxis.pdf

Drakouli, A-E., Kontele, I., Poulimeneas, D. , Saripanagiotou, S., Grammatikopoulou, M., Sergentanis, T., & Vassilakou, T. (2023). Food allergies and quality of life among school-aged children and adolescents: A systematic review. *Children, 10*, 433. https://doi.org/10.3390/children10030433

Dunn Galvin, A., Gaffney, A., & Hourihane, J. (2009). Developmental pathways in food allergies: A new theoretical framework. *Allergy, 64*, 560-568. https://doi.org/10.1111/j.1398-9995.2008.01862.x

Fenton, N., Elliott, S., Cicutto, L., Clarke, A., Haranda, L., & McPhee, E. (2011). Illustrating risk: Anaphylaxis through the eyes of the food-allergic child. *Risk Analysis, 31*(1), 171-183. https://doi.org/10.1111/j.1539-6924.2010.01488.x

Food Allergy Canada. (2024a). *Who we are.* Retrieved from http://foodallergycanada.ca/about-us/who-we-are/

Food Allergy Canada. (2024b). *Food allergy Canada (X Formerly known as Twitter)*. Retrieved from https://x.com/foodallergycan

Food Allergy Canada. (2024c). *Bullying and food allergy*. Retrieved from https://www.foodallergy.org/life-food-allergies/living-well-everyday/bullying-prevention

Food Allergy Canada. (2024d). *Sabrina's law.* Retrieved from http://foodallergycanada.ca/resources/sabrinas-law/

Food Allergy Research and Education [FARE]. (2024). *About Us*. Retrieved from https://www.foodallergy.org/about-us

Fox, J., & Warner, C. (2017). Food allergy and social anxiety in a community sample of adolescents. *Children's Health Care, 46*(1), 93-107. https://doi.org/10.1080/02739615.2015.1124773

Gadamer, H.-G. (2001). *Gadamer in conversation* (R.E. Palmer, Ed. & Trans.). Yale University Press.

Gadamer, H.-G. (1960/2013). *Truth and method* (J. Weinsheimer & D.G. Marshall, Trans.). Bloomsbury.

Gadamer, H.-G. (2007). *The Gadamer reader: A bouquet of the later writings* (R.E. Palmer, Ed. & Trans.). Northwestern University Press.

Gillespie, C., Woodgate, R., Chalmers, K., & Watson, W. (2007). "Living with risk": Mothering a child with food-induced anaphylaxis. *Journal of Pediatric Nursing, 22*, 30-42. https://doi.org/10.1016/j.pedn.2006.05.007

Golding, M., Gunnarsson, N., Middelveld, R., Ahlstedt, S., & Protudjer, J. (2021) A scoping review of the caregiver burden of pediatric food allergy. *Annals of Allergy, Asthma, and Immunology, 127*, 536–47. https://doi.org/10.1016/j.anai.2021.04.034

Herbert, L., Lin, A., Matsui, E., Wood, R., & Sharma, H. (2016). Development of a tool to measure youths' food allergy management facilitators and barriers. *Journal of Pediatric Psychology*, 363-372. https://doi.org/10.1093/jpepsy/jsv099

Huether, S.E., McCance, K.L., El-Hussein, M.T., Power-Kean, K., & Zettle, S. (2023). *Understanding pathophysiology* (2nd Canadian ed.). Elsevier.

Jennrich, J. (2010). Stigma, belonging and mothering: An outsider's understanding of disability. *Journal of the Motherhood Initiative for Research and Community Involvement, 1*(2), 64-71. https://jarm.journals.yorku.ca/index.php/jarm/article/view/31207

King, R., Knibb, R., & Hourihane, J. (2009). Impact of peanut allergy on quality of life, stress and anxiety in the family. *Allergy, 64*, 461-468. https://doi.org/10.1111/j.1398-9995.2008.01843.x

Knibb, R., Barnes, C., & Stalker, C. (2016). Parental self-efficacy in managing food allergy and mental health predicts food allergy-related quality of life. *Pediatric Allergy and Immunology, 27*, 459-464. https://doi.org/10.1111/pai.12569

Komulainen, K. (2010). Parental burden in families with a young food-allergic child. *Child Care in Practice, 16*(3), 287-302. https://doi.org/10.1080/13575271003752248

Ladd-Taylor, M. (2007). Mother-worship/mother-blame: Politics and welfare in an uncertain age. In A. O'Reilly (Ed.), *Maternal theory: Essential readings* (pp. 660-667). Demeter Press.

Lawn, C., & Keane, N. (2011). *The Gadamer dictionary*. Continuum.

Lieberman, J., Weiss, C., Furlong, T., & Sicherer, S. (2010). Bullying of pediatric patients with food allergy. *Journal of Allergy and Clinical Immunology, 105*(4), 282-86. https://doi.org/10.1016/j.anai.2010.07.011.

Loh, W., & Tang, M. (2018). The epidemiology of food allergy in the global context. *International Journal of Environmental Research and Public Health, 15*(9), 2043–50. https://doi.org/10.3390/ijerph15092043

MacKenzie, H., Roberts, G., Van Laar, D., & Dean, T. (2010). Teenagers' experiences of living with food hypersensitivity: A qualitative study. *Pediatric Allergy and Immunology, 21*(4p1), 595-602. https://doi.org/10.1111/j.1399-3038.2009.00938.x

Marklund, B., Wilde-Larsson, B., Ahlstedt, S., & Nordstrom, G. (2007). Adolescents' experiences of being food hypersensitive: A qualitative study. *BMC Nursing*, *6*(8). https://doi.org/10.1186/1472-6955-6-8

Miller, K. (2010). Activism, Maternal. In A. O'Reilly (Ed.). *Encyclopedia of motherhood*. Sage.

Minaker, L., Elliott, S., & Clarke, A. (2014). Exploring low-income families' financial barriers to food allergy management and treatment. *Journal of Allergy*, *2014,* 1-7. https://doi.org/10.1155/2014/160363

Moen, Ø., Opheim, E., & Trollvik, A. (2019). Parents experiences raising a child with food allergy: A qualitative review. *Journal of Pediatric Nursing, 46*, e52–63. https://doi.org/10.1016/j.pedn.2019.02.036

Morou, Z., Tatsioni, A., Dimoliatis, I., & Papadopoulos, N. (2014). Health-related quality of life in children with food allergy and their parents: A systematic review of the literature. *Journal of Investigational Allergology and Clinical Immunology, 24*(6), 382-95. PMID: 25668890.

Mother. (n.d.). *In Merriam-Webster dictionary*. Retrieved from https://www.merriam-webster.com/dictionary/mother

Mothers Against Drunk Driving [MADD]. (2024). *About MADD*. Retrieved from https://madd.org/our-history/

Moules, N. (2002). Hermeneutic inquiry: Paying heed to history and Hermes - An ancestral, substantive, and methodological tale. *International Journal of Qualitative Methods*, *1*(3), 1-21. Retrieved from http://ejournals.library.ualberta.ca/index.php/IJQM/article/view/4597/3750

Moules, N.J., McCaffrey, G., Field, J.C., & Laing, C.M. (2015). *Conducting hermeneutic research: From philosophy to practice*. Peter Lang.

Munoz-Furlong, A., & Weiss, C. (2009). Characteristics of food-allergic patients placing them at risk for a fatal anaphylactic episode. *Current Allergy and Asthma Reports, 9*, 57-63. https://doi.org/10.1007/s11882-009-0009-2

Ontario Ministry of Education. (2005). *Sabrina's law*. Retrieved from https://www.ontario.ca/laws/statute/05s07

O'Reilly, A. (2007). Feminist mothering. In A. O'Reilly (Ed.), *Maternal theory: Essential readings* (pp. 792-821). Demeter Press.

Parker-Pope, T. (2008). *Maternal instinct is wired into the brain*. Retrieved from https://well.blogs.nytimes.com/2008/03/07/maternal-instinct-is-wired-into-the-brain/

Primeau, M., Kagan, R., Joseph, L., Lim, H., Dufresne, C., Duffy, C., Prhcal, D., & Clarke, A. (2000). The psychological burden of peanut allergy as perceived by adults with peanut allergy and the parents of peanut-allergic children. *Clinical and Experimental Allergy, 30*, 1135-1143. https://doi.org/10.1046/j.1365-2222.2000.00889.x

Protudjer, J.L., Jansson, S.A., Middelveld, R., Östblom, E., Dahlén, S.E., Arnlind, M.H., Bengtsson, U., Kallström-Bengtsson, I., Marklund, B., Rentzos, G., Sundqvist, A.C., Åkerström, J., & Ahlstedt, S. (2015). Household costs associated with objectively diagnosed allergy to staple foods in children and adolescents. *Journal of Allergy and Clinical Immunology: In Practice, 3*(1), 68-75. https://doi.org/10.1016/j.jaip.2014.09.021

Ruddick, S. (2007). Maternal thinking. In A. O'Reilly (Ed.), *Maternal theory: Essential readings* (pp. 96-113). Demeter Press.

Saleh-Langenberg, J., Flokstra-de Blok, B., Goossens, N., Kemna, J., van der Velde, J., & Dubois, A. (2016). The compliance and burden of treatment with the epinephrine auto-injector in food-allergic adolescents. *Pediatric Allergy and Immunology, 27*, 28-34. https://doi.org/10.1111/pai.12458

Shemesh, E., Annunziato, R., Ambrose, M., Ravid, N., Mullarkey, C., Rubes, M., Chuang, K., Sicherer, M., & Sicherer, S.H. (2013). Child and parental reports of bullying in a consecutive sample of children with food allergy. *Pediatrics, 131*, e10-e17. https://doi.org/10.1542/peds.2012-1180

Sicherer, S., Noone S., & Muñoz-Furlong A. (2001). The impact of childhood food allergy on Quality of Life. *The Annals of Allergy, Asthma, and Immunology, 87*(6), 461-464. https://doi.org/10.1016/S1081-1206(10)62258-2

Singh, I. (2004). Doing their jobs: Mothering with Ritalin in a culture of mother-blame. *Social Science and Medicine, 59*, 1193-1205. https://doi.org/10.1016/j.socscimed.2004.01.011

Soller, L., Ben-Shoshan, M., Harrington, D., Fragapane, J., Joseph, L. St. Pierre, Y., Godefroy, S.B., La Vieille, S., Elliott, S.J., & Clarke, A. (2012). Overall prevalence of self-reported food allergy in Canada. *Journal of Allergy and Clinical Immunology, 130*(4), 986–8. https://doi.org/10.1016/j.jaci.2012.06.029

Sommer, I., MacKenzie, H., Venter, C., & Dean, T. (2014). An exploratory investigation of food choice behavior of teenagers with and without food allergies. *Annals of Allergy and Immunology, 112*, 446-452. https://doi.org/10.1016/j.anai.2014.02.009

Stensgaard, A., Bindslev-Jensen, C., & Nielsen, D. (2016). Peanut allergy as a family project: Social relations and transitions in adolescence. *Journal of Clinical Nursing*, 1-11. https://doi.org/10.1111/jocn.13696

Take a backseat. (n.d.) In *Farlex dictionary of idioms*. (2015). Retrieved from https://idioms.thefreedictionary.com/take+a+back+seat

Tanno, L., Clark, E., Mamodaly, M., Cardona, V., Ebisawa, Asontegui, I., Sanchez-Borges, M., Santos, A.F., Fiocchi, A., Worm, M., Caimmi, D., Latour Staffeld, P., Muraro, A., Pawankar, R., Greenberger, P.A., Thong, B.Y., Martin, B., & Demoly, P. (2021). Food-induced anaphylaxis morbidity: Emergency department and hospitalization data support preventive strategies. *Pediatric Allergy and Immunology, 32*(8),1730–42. https://doi.org/10.1111/pai.13578

The Peace Alliance. (2018). *History of Mother's Day as a day of peace: Julia Ward Howe*. Retrieved from https://peacealliance.org/history-of-mothers-day-as-a-day-of-peace-julia-ward-howe/

Thurer, S. (2007). The myths of motherhood. In A. O'Reilly (Ed.), *Maternal theory: Essential readings* (pp. 331-344). Demeter Press.

Warren, C., Dyer, A., Otto, A., Smith, B., Kauke, K., Dinaker, C., & Gupta, R. (2017). Food allergy-related risk-taking and management behaviors among adolescents and young adults. *Journal of Allergy and Clinical Immunology: In Practice, 5*, 381-390. https://doi.org/10.1016/j.jaip.2016.12.012

Wassenberg, J., Cochard, M., DunnGalvin, A., Ballabeni, P., Flokstra de-Blok, B., Newman, C., Hofer, M., & Eigenmann, P. (2012). Parent perceived quality of life is age-dependent in food allergy. *Pediatric Allergy and Immunology, 23*, 412-419. https://doi.org/10.1111/j.1399-3038.2012.01310.x

Williams, C. (2000). Alert assistants in managing chronic illness: The case of mothers and teenage sons. *Sociology of Health and Illness, 22*(2), 254-272. https://doi.org/10.1111/1467-9566.00202

Williams, N., Parra, G., & Elkin, T. (2009). Subjective distress and emotional resources in parents and children with food allergy. *Children's Health Care, 38*, 213-227. https://doi.org/10.1080/02739610903038792

Wilson-Forrest, K. (2007). *"Never really free": Anaphylaxis and the family leisure experience*. (Master's thesis). Retrieved from http://search.proquest.com

World Health Organization. (2009). *Child and adolescent health development: Progress report.* WHO Press. Retrieved from https://iris.who.int/bitstream/handle/10665/44314/9789241599368_eng.pdf?sequence=1&isAllowed=y

Wright, L., & Leahey, M. (2013). *Nurses and families: A guide to family assessment and intervention* (6th ed.). F.A. Davis.

Xu, Y., Kastner, M., Harada, L., Xu, A., Salter, J., & Waserman, S. (2014). Anaphylaxis-related deaths in Ontario: A retrospective review of cases from 1986-2011. *Allergy, Asthma, and Clinical Immunology, 10*, 38-45. https://doi.org/10.1186/1710-1492-10-38