

**Parents' Lived Experience with Epinephrine use During their Child's
Anaphylactic Reaction: An Interpretive Phenomenology**

by

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Abstract

Children with life-threatening food allergies live with the constant threat of a fatal reaction, and caregivers must always be prepared to treat with an epinephrine auto-injector (EAI). This interpretive phenomenological study explored parents' perceptions and lived experiences with prescribed EAI use for their child. The purposive sample included 10 parents of five children under 12 years of age, diagnosed with a food allergy and prescribed with an EAI who recently experienced anaphylaxis. Eight main themes emerged: perception of anaphylaxis, life challenges, isolation, anxiety, hesitation, guilt, influence of health care, and lessons learned. Parents described multiple life challenges and feelings of isolation, anxiety and hesitation during a reaction that lead to subsequent guilt. Handling reactions correctly provided parents with confidence to treat subsequent reactions. Witnessing the effects of an EAI and receiving positive feedback from health care providers further strengthened their confidence to quickly and competently intervene in future reactions.

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Dedication

My thesis is dedicated to my biggest fans, Papa (Surend Chooniedass) and Gram (Yvonne Dass). I'm glad that you both saw me start this journey and supported me when I thought things were difficult. I know that you would both be proud to see this accomplishment.

Table of Contents

Abstract	i
Acknowledgements	ii
Dedication.....	iii
List of Tables	vi
List of Figures	vii
Chapter 1: Introduction	1
Problem Statement	1
Study Purpose	3
Study Definitions.....	4
Chapter 2: Review of the Literature	6
Food Allergy.....	6
Anaphylaxis	7
Epinephrine	9
Barriers to Epinephrine Use.....	13
Quality of Life	17
Caregiver Responsibility.....	18
Food Allergy Education.....	19
Summary.....	22
Chapter 3: Methodology.....	23
Study Purpose	23
Research Question.....	23
Theoretical Framework	23
Study Design	24
Sample	25
Inclusion criteria.....	25
Exclusion criteria.....	25
Sampling method and recruitment.....	25
Sample size and saturation.....	26
Data Collection and Analysis	26
Ethical Considerations	29
Chapter 4: Findings.....	30
Demographics	30
Table 1. Study participant demographics.....	30
Table 2. Child demographics.....	31
Themes	32
Perception of anaphylaxis.....	32
Life challenges.....	33
Isolation.....	35
Anxiety.....	37
Hesitation.....	40
Guilt.....	42
Influence of health care professionals.....	43
Lessons learned.....	46
Responses to Caring for a Child with Food Allergy	49

Chapter 5: Discussion	50
Educational Information	50
Education after a diagnosis.....	50
Educational methods.....	52
Emotional Impact.....	53
Length of time living with food allergies.....	53
Responses to caring for a child with a food allergy.....	54
Life with multiple food allergies.....	54
Emotions experienced when using an EAI.....	55
Influence of caregivers.....	56
Health Care Professionals.....	57
Challenges of daily life.....	58
Interactions with health care providers.....	58
Inconsistent advice.....	60
Knowledge to Action Cycle and Results of this Study	61
Study Strengths and Limitations	63
Implications for Practice, Policy and Education.....	64
Implications for Research.....	64
Summary.....	65
References	67
APPENDICES	81
Appendix A - Consent Form.....	81
Appendix B - Demographics Form	84

List of Tables

Table 1. Study participant demographics.....	30
Table 2. Child demographics.	31
Table 3. Emotions by gender.	49

List of Figures

Figure 1. Signs and symptoms of food allergy	8
Figure 2. Clinical criteria for diagnosing anaphylaxis.....	10
Figure 3. Knowledge to Action cycle.....	24
Figure 4. Emerging themes.....	32

Chapter 1: Introduction

Food allergy has a significant impact on quality of life, and is the cause of morbidity and mortality across all ages. This chapter will provide the necessary background, foundation and purpose of this study. This chapter identifies the need to conduct a qualitative study that describes root cause(s) of failing to treat anaphylactic reactions in order to better manage the health of children with food allergies.

Problem Statement

Food allergies cost approximately 25 billion dollars (USD) annually (Gupta et al., 2013) and the cost is only increasing as food allergies are on the rise (Branum & Lukac, 2008). This medical condition is creating a global concern as it significantly affects quality of life in patients and their families. Patients can be allergic to a single food, or multiple foods. Most food allergies are often discovered by accidental exposure that leads to a severe reaction and an emergency room visit.

Foods have been identified as one of the most common causes of anaphylaxis (Lieberman & Teach, 2008). Anaphylaxis is a severe allergic reaction that can affect multiple organ systems in the body and can rapidly cause death. The symptoms of anaphylaxis can be mild, moderate or severe contributing to confusion when identifying a reaction (McLean-Tooke et al., 2003). Anaphylaxis admissions in Canadian Emergency Departments have doubled over the course of four years (Hochstadter et al., 2016). Despite patients having a diagnosis of anaphylaxis, treatment in the community is still consistently neglected or withheld (Abdurrahman et al., 2013). This is particularly concerning in our most vulnerable population - children.

Caregivers are the primary source of daily safety and protection for children. Caregivers of children living with life-threatening allergies are responsible for their child's health

management (Annunziato et al., 2015). Many caregivers worry for their child's safety when they are not in their presence (Turjanmaa, 2001); however, the majority of reactions to food occur within the child's home (Moneret-Vautrin et al., 2001). This medical condition has been considered "an acute and chronic" life stressor (Shanahan, Zucker, Copeland, Costello, & Angold, 2014, p. 468). Individuals with a diagnosis of a life-threatening food allergy live with the constant threat of a fatal anaphylactic reaction (Sampson, Muñoz-Furlong, & Sicherer, 2006; Zijlstra et al., 2010).

Presently, there is no cure for food allergies. Epinephrine is the primary medical treatment recommended for an anaphylactic reaction for both pediatric and adult populations (Lieberman et al., 2005). Patients are prescribed a pre-filled epinephrine auto-injector (EAI) when they are diagnosed with a severe food allergy. Patients must always be prepared to treat themselves with this injectable life-saving medication and ensure others around them know how to treat, in the event they are incapacitated (Avery, King, Knight, & Hourihane, 2003). Despite this knowledge, caregivers often do not use this life-saving medication, risking severe and possibly fatal consequences (Abdurrahman et al., 2013; Song, Worm, & Lieberman, 2014).

Patients frequently receive inadequate treatment, and caregivers often do not have timely access to resources to manage reactions (Abdurrahman et al., 2013). A study reviewed fatal anaphylactic reactions and found that only 10% of patients had carried an EAI and none used it (Bock, Muñoz-Furlong, & Sampson, 2007). Rates of epinephrine use during an anaphylactic reaction are alarmingly low and treatment is often inappropriately managed (Song, Worm, & Lieberman, 2014), while treatment in children is often withheld. The reasons range from not carrying an EAI when a reaction is occurring to caregivers not wanting to administer medication if they are unsure of themselves or the situation. It is alarming that despite educational programs

and guidelines on EAI use for patients experiencing anaphylaxis, treatment rates remain low. A study showed children who experienced recurrent anaphylaxis only used an EAI 29% of the time (Gold & Sainsbury, 2000). Some speculate that injecting epinephrine into their child is a traumatic event and this may contribute to the profound lack of treatment (Kazak, Schneider, & Kassam-Adams, 2009). It is crucial to understand the root cause(s) of failing to treat anaphylactic reactions in order to better manage the health of children with food allergies.

Unsworth (2001) states, “comprehensive and helpful published advice on patient training (for EAI) is available, but compliance remains poor” (p.410). There is an urgent need to better understand the barriers associated with treatment to improve self-efficacy and appropriate management. If health care providers are to improve outcomes of anaphylactic reactions, then researchers must identify why caregivers hesitate or neglect to use EAIs. The current educational programs are ineffective. There is a lack of research exploring experiences and attitudes related to managing food allergies and the use of EAIs (Money, Barnett, Kuljis, & Lucas, 2013). By understanding the thoughts and emotions of parents who have experienced their child’s anaphylactic reaction, health care providers can ensure that caregivers acquire the skills and education necessary to make certain that the next reaction is appropriately treated.

Study Purpose

The purpose of this interpretive phenomenological study is to describe parents’ perceptions and lived experiences with epinephrine use during a child’s anaphylactic reaction. This research is required to better understand the factors associated with caregivers’ use of an EAI on their child. This study provides insights on how best to educate, assist and promote the correct and prompt use of EAIs for all caregivers. By understanding why EAI are not used

during a reaction, educational strategies may be developed to ensure patients and caregivers are able and willing to treat life-threatening reactions appropriately.

Study Definitions

Researchers suggest the provision of clear definitions of the main terms in order to avoid a misunderstanding of a construct, and for the purpose of clarifying meanings (Vivar, McQueen, Whyte, & Armayor, 2007). Clarification of the meaning of the key constructs ensures transparency of the study and allows the researcher to understand the specific context of the phenomenon under study. Main constructs are defined in this section.

Allergic reaction: An immune response that occurs when the body encounters a foreign allergen, causing antibodies to react and promote the release of mediators. This causes clinical symptoms ranging from urticaria to anaphylaxis.

Anaphylaxis: A serious systemic allergic reaction that occurs rapidly and is potentially fatal. Common triggers for anaphylaxis are food, insect stings and medication.

Caregivers: Parents, family members, guardians, babysitters and school staff who take care of a child.

Epinephrine: A hormone secreted from the adrenal glands to produce a fight or flight response by increasing blood flow. Also referred to as adrenalin.

Epinephrine Auto-Injector (EAI): A prefilled syringe used to deliver a measured quantity of medication (epinephrine) during an anaphylactic reaction.

Food allergy: An adverse health effect arising from a specific immune response that occurs reproducibly on exposure to a given food. A physician diagnoses a patient to be food allergic after taking a medical history, often followed by a positive skin-prick test and blood IgE test to

the specific allergen. A food allergy diagnosis may sometimes include an oral food challenge to the specific food.

Chapter 2: Review of the Literature

This chapter provides a review of the literature that forms the basis for this study. A review of current literature on food allergy and anaphylaxis is presented. In order to justify the need for the study, it was important to perform an analysis of existing literature to identify gaps in knowledge about caregivers' experiences of EAI use. It will stress the impact that food allergy has on the quality of life of children and their caregivers. Treatment for anaphylaxis will be reviewed and barriers to treatment will be highlighted. This chapter provides a clearly defined logic for a research study, and helps to establish a firm background for the research question being investigated (Sandelowski & Barroso, 2003).

Food Allergy

Food allergy has increased two to threefold in the last twenty years and is associated with increased anxiety, poor quality of life, and increased health care costs including emergency visits and hospital admissions (Branum & Lukac, 2008; Cummings, Knibb, Erlewyn-Lajeunesse, et al., 2010). Over the last decade food allergy has become a global health burden (Carrard, Rizzuti, & Sokollik, 2015). Misinformed perceptions and widespread self-reports of food allergies have made the term 'food allergy' very common, however this does not often correlate to a true allergy (Sicherer, 2011). The Journal of Allergy and Clinical Immunology Guidelines for the Diagnosis and Management of Food Allergy states that, "a food allergy is defined as an adverse health effect arising from a specific immune response that occurs reproducibly on exposure to a given food" (Boyce et al., 2010, p. 8).

Many health researchers postulate that children who develop food allergies are born with certain immune makers making them more predisposed than others (Bird, 2016). In food allergies, the body's immune system reacts to proteins in food (Moriyama, 2015). The first time

the body encounters an allergenic food protein, it makes IgE antibodies against the protein. When the allergenic food is subsequently ingested, IgE antibodies bound to allergy associated cells (mast cells, basophils, and eosinophils) activate these cells to react and release preformed mediators, such as histamine, and induce production of newly generated mediators such as prostanoids and leukotrienes that cause allergic symptoms (Waserman & Watson, 2011). The higher the concentration of IgE antibodies to a specific food allergen, the higher the risk for a reaction (Sampson, 2001). Common signs and symptoms of food allergy can include skin symptoms (urticaria, pruritus, erythema or angioedema), gastrointestinal symptoms (abdominal cramping, nausea, vomiting, or diarrhea), or respiratory symptoms (nasal congestion, rhinorrhea, cough, wheeze) (Sampson, 2005). A detailed list of signs and symptoms can be found in Figure 1 below.

Approximately 8% of children in North America have a food allergy (Sicherer & Sampson, 2014). The most common food allergies include: egg, milk, peanut, tree nuts, wheat, soy, fish, shellfish and sesame (Bird, Lack, & Perry, 2015). A Canadian study showed that 85% of all anaphylaxis cases were triggered by a food, the majority of which were due to peanut, milk, or egg (Ben-Shoshan et al., 2013).

Anaphylaxis

Although anaphylaxis is a well-documented clinical condition, there is no universally accepted definition for it (Sicherer & Simons, 2007) and these life-threatening reactions have become a worldwide concern. “Food-induced anaphylaxis is a rapidly progressive, multi-organ allergic reaction that can result in death” (Bird et al., 2015, p. 7). Reactions involving skin symptoms such as urticaria, itching, flushing and angioedema are present 80% of the time in children (Sicherer & Simons, 2007). This medical condition occurs without warning, has

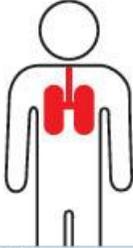
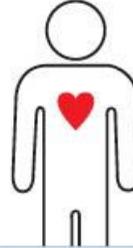
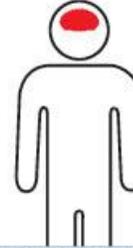
				
SKIN	RESPIRATORY	GASTROINTESTINAL	CARDIOVASCULAR	NEUROLOGICAL
hives, swelling, itching, warmth, redness	coughing, wheezing, shortness of breath, chest pain or tightness, throat tightness, trouble swallowing, hoarse voice, nasal congestion or hay fever-like symptoms, (sneezing or runny or itchy nose; red, itchy or watery eyes)	nausea, stomach pain or cramps, vomiting, diarrhea	dizziness/ lightheadedness, pale/blue colour, weak pulse, fainting, shock, loss of consciousness	anxiety, feeling of "impending doom" (feeling that something really bad is about to happen), headache
				OTHER^{2,3}
				uterine cramps

Figure 1. Signs and symptoms of food allergy (with permission from Food Allergy Canada).

potential fatal consequences, and demands attention from all health care providers and caregivers.

“Anaphylaxis remains an important cause of mortality” (McLean-Tooke, Bethune, Fay, & Spickett, 2003, p. 1332). According to the Food Allergy & Anaphylaxis Network (now known as the Food Allergy Research & Education organization), anaphylaxis accounts for approximately 200 deaths annually in the United States, but there is no current accurate data on anaphylactic deaths in Canada (Waserman & Watson, 2011). The prevalence of anaphylaxis is difficult to determine. Chart reviews can provide some information, but the diagnosis of anaphylaxis is often not clearly charted (Ben-Shoshan et al., 2013). One significant difficulty with identifying anaphylaxis is its variable of signs and symptoms; anaphylaxis can manifest differently in the same person, even when triggered by the same allergen. Signs and symptoms of anaphylaxis are often confused with asthma, choking, panic disorder or vasovagal syncope

(Sicherer & Simons, 2007). A study showed that children with a peanut allergy who experienced skin symptoms with their first reaction, experience more severe symptoms with their subsequent reaction (Vander Leek, Liu, Stefanski, Blacker, & Bock, 2000). Often symptoms are not immediately recognized, as they may be external and visible to others (hives) or internal where symptoms are experienced within the body (bronchoconstriction). This is one reason anaphylaxis is often inadequately or improperly treated (Gold, Sussman, Loubser, & Binkley, 1995). Health care providers cannot expect caregivers to recognize signs and symptoms of anaphylaxis and subsequently treat a reaction if they are unable to identify it in the first place (Sicherer & Simons, 2007). As such, specific criteria have been put in place to better identify anaphylaxis.

The majority of anaphylactic reactions are uniphasic early allergic responses, occurring minutes after exposure and typically subside with time. Others reactions are biphasic, in which a second wave of symptoms return (a late allergic response), or reactions can be protracted, where symptoms develop hours to days after exposure. During a reaction, there may be development of new symptoms which can occur in up to 20% of patients (Rohacek, Edenhofer, Bircher, & Bingisser, 2014). The lack of prompt epinephrine administration has an increased risk for a biphasic reaction. It is crucial to educate caregivers about prompt EAI administration and explain the importance of proceeding to an emergency department for continued monitoring.

Epinephrine

The first emergency medication indicated in the treatment of anaphylaxis is epinephrine. Epinephrine (also known as adrenalin) is effective, universally available and affordable even in low-resource countries (Simons & Simons, 2010).

Experts in the field of allergy and clinical immunology around the world unanimously agree that prompt administration of epinephrine is the first line of treatment for anaphylaxis

Anaphylaxis is highly likely when any 1 of the following 3 criteria are fulfilled:	
1. Acute onset of an illness (minutes to several hours) with involvement of the skin, mucosal tissue, or both (eg. generalized hives, pruritus or flushing, swollen lips-tongue-uvula) AND at least 1 of the following:	
	a. Respiratory compromise (eg. dyspnea, wheeze-bronchospasm, stridor, reduced PEF, hypoxemia)
	b. Reduced BP or associated symptoms of end-organ dysfunction (eg. hypotonia (collapse), syncope, incontinence)
2. Two or more of the following that occur rapidly after exposure to a likely allergen for that patient (minutes to several hours):	
	a. Involvement of the skin-mucosal tissue (eg. generalized hives, itch-flush, swollen lips-tongue-uvula)
	b. Respiratory compromise (eg. dyspnea, wheeze-bronchospasm, stridor, reduced PEF, hypoxemia)
	c. Reduced BP or associated symptoms (eg. hypotonia (collapse), syncope, incontinence), persistent gastrointestinal symptoms (eg. crampy abdominal pain, vomiting)
3. Reduced BP after exposure to known allergen for that patient (minutes to several hours):	
	a. Infants and children: low systolic BP (age specific) or greater than 30% decrease in systolic BP*
	b. Adults: systolic BP of less than 90 mm/Hg or greater than 30% decrease from that person's baseline

Figure 2. Clinical criteria for diagnosing anaphylaxis (replicated from Sampson, Muñoz-Furlong, et al., 2006).

(Song, Worm, & Lieberman, 2014). Currently the World Health Organization and the World Allergy Organization consider epinephrine to be an essential medication for anaphylaxis treatment (Kemp, Lockey, & Simons, 2008). Guidelines from both the American Academy of Allergy, Asthma and Immunology and the American College of Allergy, Asthma and Immunology recommend prompt administration of epinephrine at the first indication of signs and symptoms of anaphylaxis, and go as far as to suggest administering the medication even when in doubt (Sicherer & Simons, 2007; Song et al., 2014).

In hospital settings, epinephrine is drawn up from ampules into syringes. However, even caregivers without access to or experience with medical equipment or techniques must be able to administer this medication when needed. Syringes prefilled with measured epinephrine, known as EAI's, have been developed for convenience and quick administration. EAI's have preset epinephrine dosing for patients weight <25kg there is a 0.15mg of epinephrine and needle length of 1.3 cm and for patients weighing >25kg there is a 0.3mg dose of epinephrine with a needle length of 1.6 cm (Song & Lieberman, 2015). A 22 gauge needle size is used for both doses ("epipen frequently asked questions", May 2016). Intra-muscular administration of epinephrine to different sites on the body has different rates of absorption, contributing to varying times to peak plasma concentrations (Sicherer & Simons, 2007). Injection to the mid-lateral thigh has proven to be the route of choice (Frew, 2011; Stecher, Bulloch, Sales, Schaefer, & Keahey, 2009). The large muscle allows for rapid absorption. The average time of the pharmacological onset of epinephrine is eight minutes (Simons, 2011). When epinephrine is given in a timely manner, it has been proven to reduce morbidity and thereby decreasing hospitalization (Gold & Sainsbury, 2000).

There is substantive evidence to show the benefits of epinephrine during anaphylaxis. Epinephrine reduces swelling of the airways and decreases bronchoconstriction (Simons, 2011). There are no contraindications to the use of epinephrine for a life-threatening allergic reaction (Simons, 2009). Auto-injectors contain a relatively low dose of epinephrine and possible side effects are minimal and inconsequential when compared to the known course of untreated anaphylaxis. Epinephrine should be used for anaphylaxis regardless of the severity of the reaction (Ben-Shoshan et al., 2013). In cases where the patient has a history of a severe reaction and has known exposure to an allergen, epinephrine may be given even before symptoms

develop (Gold et al., 1995). Fatalities occur when epinephrine use is delayed or omitted altogether (Sampson, Mendelson, & Rosen, 1992). A retrospective study in Ontario identified 80 deaths from anaphylaxis between 1986-2000, and reported that only 22% had been prescribed an EAI (Xu, Wasserman, Harada, & Kastner, 2012). Sicherer and Simons (2007) identified 13 children who experienced anaphylaxis to food, six of which were fatal due to delayed epinephrine administration. The seven children who survived, were treated with epinephrine within the first five minutes of the reaction. This emphasizes the importance of prompt administration of epinephrine. Storey (2015) states “it is not clear why adrenalin is withheld in the face of anaphylaxis” (Storey & Fitzharris, 2015, p. 1).

Adverse effects of epinephrine include tremor, increase heart rate, sweating, feelings of anxiety, transient pallor, nausea and vomiting (Sicherer & Simons, 2007). These symptoms resolve quickly. In rare cases or in cases of an overdose, a patient may have ventricular arrhythmias, angina, myocardial infarction, pulmonary edema or intracranial hemorrhage (Simons, 2004). However, Simons (2004) states there is “no absolute contraindication to epinephrine use in anaphylaxis” (p. 837). EAI's have a low dose of epinephrine that will not harm a patient if accidentally used, but can save a life during anaphylaxis.

Clinical guideline compliance remains poor even when the benefits are clear (Prior, Guerin, & Grimmer-Somers, 2008). Multiple studies conducted have illustrated the inconsistent management of anaphylaxis despite clear recommendations. A study of Canadian children from 2004-2009 with physician confirmed peanut allergy, showed that severe reactions were treated with epinephrine only 21% of the time (Nguyen-Luu et al., 2012). Similarly, another Canadian study showed that only four of 20 children who experienced a moderate to severe food allergic reaction received epinephrine (Yu et al., 2006). These studies illustrate the need for improved

compliance and knowledge translation to health care providers and caregivers. Despite worldwide clinical practice guidelines, treatment of anaphylaxis is still not appropriately managed by hospitals, clinics and other health care organizations (Song et al., 2014).

Barriers to Epinephrine Use

The words, “multiple and complex” are used to describe the barriers to epinephrine use (Gallagher, Worth, Cunningham - Burley, & Sheikh, 2011). Curtis et al. (2014) outlines the barriers to epinephrine use and states that medical professionals should “reassess what measures can be taken to help improve epinephrine availability to food-allergic children” (p. 561).

The first important barrier to identify is the lack of EAI prescriptions (Simons, Clark, & Camargo, 2009). A study showed that despite having a systemic allergic reaction, patients did not receive a prescription for an EAI (Goldberg & Confino-Cohen, 2000). A prescription for an EAI is provided when there has been a history of an anaphylactic reaction (Sicherer & Simons, 2007). Physicians need to prescribe EAIs for reactions which occur outside a hospital or clinic setting, such as at emergency room visits (Sicherer & Simons, 2007). Unfortunately, patients are often discharged from emergency departments without a prescription for an EAI, education, or referral to a specialist (Campbell et al., 2008). Without a prescription, one cannot obtain an EAI with medical coverage. If a prescription is given but one cannot afford it, the hospital often advises them to ask friends or family for financial assistance (T. Furst, personal communication, October.28, 2014). Hospitals do not stock EAIs, and therefore cannot give one to patients in need. Discharging an underprivileged patient with a prescription for an EAI after describing that this reaction can be fatal, without ensuring they have the means to acquire an EAI is problematic.

A pervasive lack of knowledge related to how patients use EAIs has been documented (Arkwright & Farragher, 2006; Pouessel et al., 2006). A study reported that of the patients who

are given a prescription, only half of physicians provided education regarding EAI administration while only 7% demonstrated the technique (Mehr, Robinson, & Tang, 2007). With only half of physicians providing education, many caregivers are left uninformed about how and when to treat a reaction. Another study identified adolescents who experienced a severe reaction and found the majority of adolescents and their parents did not use their EAIs despite having it present (Gallagher et al., 2011). This suggests that carrying an EAI does not guarantee it will be utilized in an emergency situation.

Although EAIs are designed to make administration easy, errors are still possible (Sicherer & Simons, 2007). The most common cause of deaths from food allergies is delayed administration of epinephrine (Sicherer & Simons, 2007). A hospital-based pharmacist discussed a common scenario where paramedics administered an EAI prior to hospital arrival. The pharmacist noted that at times the EAI is incorrectly landmarked on the upper arm instead of the outer thigh (T. Furst, personal communication, October.28, 2014). It is routine practice to teach parents to administer the auto-injector in the lateral thigh, the largest muscle in the body, allowing for rapid absorption. If patients or caregivers observe a group of trained health care professionals using the EAI on an alternate site, it may confuse and undermine previous training. This information strongly suggests the urgent need to consistently educate healthcare providers, patients and caregivers on the proper use of epinephrine and to implement guidelines that highlight this medication as a first line treatment.

Of the minority of patients who receive education on the importance of EAI, most still do not carry one with them (Wüthrich & Ballmer-Weber, 2001). A study revealed that although patients have been taught about EAIs only 18% were allowed practice with a placebo trainer device (Goldberg & Confino-Cohen, 2000). Sicherer and colleagues (2007) state, “review and

practice of injection technique using trainers and review of manufacturer's educational materials are strongly recommended" (p. 644). It is one thing to train caregivers and practice treatment, but if the treatment is not delivered in the time of need, it is not helpful. The study also showed that only 42% of caregivers of children 12 years and younger were able to accurately demonstrate correct EAI technique (Goldberg & Confino-Cohen, 2000). Even though caregivers may think they can administer this life-saving medication, less than half are actually using it correctly. Another study showed that there was a positive correlation between competency of epinephrine use and regular visits to see an Allergist (Topal et al., 2012). Accuracy of epinephrine use decreased as the time of initial demonstration to last visit increased.

Few qualitative studies were located that examined factors associated with epinephrine use. One study considered both positive and negative aspects with epinephrine auto-injectors and found that although carrying it provides a sense of security, it is inconvenient and some patients refuse to use it due to possible side effects (Elberink, Van der Heide, Guyatt, & Dubois, 2006). Ben-Shoshan and colleagues (2013) identified some reasons for parents not using an EAI, which included hesitation, panicked and fear of the needle. They speculate that when a child experiences a moderate or severe anaphylactic reaction, parents get so distressed that they become too anxious to appropriately use the EAI (Ben-Shoshan et al., 2013). Although barriers are important to identify as reasons for noncompliance, understanding factors that promote proper management are equally important for health care providers to teach others. Action plans are written guidelines provided to patients to help manage a reaction. These plans inform caregivers to take the child to the emergency department after experiencing a reaction (Sicherer & Simons, 2007). Kim and colleagues acknowledge that a psychological component may be related to EAI use (Kim, Sinacore, & Pongracic, 2005). For instance, some parents may think

that if epinephrine is administered it is very serious because you must go to the hospital. This standard practice is taught so that caregivers will present to the emergency department in case symptoms return or worsen. However, it is possible that caregivers may think that this recommendation is made because the medication contained in EAI is dangerous and only hospitals can treat the side effects associated with the medications. These incorrect assumptions may contribute to hesitation and anxiety with epinephrine administration. Another study emphasized the importance of food allergy education as family members of patients who had fatal reactions described that their family member never used epinephrine in the past nor had a hospital visit (Bock, Muñoz-Furlong, & Sampson, 2007). It may be a common misperception for caregivers to think that reactions will not escalate based on previous reactions, giving caregivers and children a false sense of security. On the other hand, one would assume that after experiencing severe anaphylactic reaction, the patient or caregiver would know to treat promptly. However, one study showed that only 12% of children who were prescribed an EAI, with a history of a severe anaphylactic reaction involving the cardiovascular or respiratory systems, used their EAI for subsequent reactions (Gold & Sainsbury, 2000). Given the history of a previous severe experience, one should assume that no one would ever want their child to experience similar life-threatening experience, so identifying reasons for lack of treatment is imperative. A study has shown that 22% of patients experiencing an anaphylactic reaction requiring an EAI were too scared to self-administer, and this percentage doubles for children aged 12 or younger (Goldberg & Confino-Cohen, 2000). Due to the multiple and complex barriers associated with EAI use, it is crucial to gain a better understanding from parents about their use or non-use of this medication in order to overcome the obstacles.

Quality of Life

Learning that a child has been diagnosed with a food allergy can be a complex and overwhelming process (Mandell, Curtis, Gold, & Hardie, 2002). Parental responses at the time of diagnosis include a wide range of emotions and thoughts including fear, guilt and sadness (Gillespie, Woodgate, Chalmers, & Watson, 2007). Several studies have illustrated that the diagnosis of a life-threatening food allergy can have a significant impact upon an individual's life to the extent that an overall decrease in quality of life occurs for not only the patient, but also for the family (Cummings, Knibb, King, & Lucas, 2010).

Many families have had to make significant changes to their lifestyle in order to keep a food allergic family member safe. Parents stop eating at restaurants, decrease social activities with their child and even reduce working hours or quit their job entirely after their child is diagnosed with a food allergy. Extreme vigilance contributes to increased anxiety and a poor quality of life (Sicherer, Furlong, DeSimone, & Sampson, 2001). Unnecessary elimination diets may lead to nutrient deficiency and anxiety (Zijlstra et al., 2010). The perceived quality of life for food allergic patients and their families is lower than the average quality of life found in the general population and lower than that found in non-allergic patients living with other chronic diseases such as diabetes mellitus, asthma, rheumatoid arthritis and irritable bowel syndrome (Flokstra-de Blok et al., 2009).

Health related quality of life encompasses physical aspects of the illness and treatment as well as its effect on the person or family's social and psychological functioning (Cummings, Knibb, King, et al., 2010). Management of this disease can be challenging because of the possibility of unintentional exposures (Kagan et al., 2003). Parents and caregivers are key players that are associated with reactions, as they are often in charge of meal preparation for

children (Williams, Parra, & Elkin, 2009). Knibb and colleagues (2008) conducted a study that showed food allergic patients had a lower quality of life due to higher levels of stress and poor coping skills. Stress affects the patient and also impacts all those involved in the patient's care. Studies have shown that children living with food allergies have increased health disorders, such as generalized anxiety (King, Knibb, & Hourihane, 2009; Shanahan, Zucker, Copeland, Costello, & Angold, 2014, p. p.468).

Numerous studies have focused on the child's quality of life, but there has been less exploration into the caregiver's perception (Williams & Hankey, 2015). Parenting is a difficult job most times, but caregivers of children living with food allergies have additional, often challenging responsibilities. Label reading, preparing for social activities, informing schools and other caregivers about this medical condition are a full time responsibility. The liberty of taking a 'day off' does not exist for caregivers of children with a food allergy, as the consequences could be fatal.

Caregiver Responsibility

Families are not all the same; some are comprised of single parent, divorced parents, multigenerational families, and same sex families. This may lead one to question 'who is responsible for a child's food allergy?'. While some studies focusing on mothers have shown associations between higher levels of stress and anxiety in food allergic children and their mothers, it has also been shown that quality of life is reduced for both mothers and fathers (Bartnikas & Phipatanakul, 2015; Lyons & Forde, 2004; Primeau et al., 2000). Since few studies have shown significant differences between mothers' and fathers' ability to manage their child's food allergy, more studies are required to better understand why this difference exists (Warren et al., 2015a). In the past, more emphasis was placed on mothers, as they were predominately

responsible for a child's health. Mandell (2002) described that fathers and other caregivers believed a child's medical health was the mother's responsibility. However over the last few decades, there has been a societal change in which women are working full time and more males are staying home to raise children. There is no longer a gender-defined role of health care provider within a family. In today's society, employers permit maternity and paternity leave, as well as time away from work for family illness. It is becoming more common to see both parents at medical appointments and well informed about their child's health.

Clark and Thompson (2012) described parents' anxiety with epinephrine auto-injectors administration. Parental anxiety can hamper a child's perception of risk (Akeson, Worth, & Sheikh, 2007; Rouf, White, & Evans, 2011). Conversely, a parent's positive approach to coping has been shown to help alleviate anxiety (Gillespie et al., 2007). Examining patient's beliefs and experiences with epinephrine use not only involves examining negative feelings and barriers to use, but also uncovers positive approaches to epinephrine use. Gaining understanding from parents with positive experiences can help provide insight and tools for other caregivers.

Food Allergy Education

Patients often receive inadequate treatment from health care providers, and do not have timely access to resources to manage their reactions (Abdurrahman et al., 2013). In addition to educating the patient, education of family and friends provides additional support (Bock et al., 2007). The more the public is aware of food allergies and its treatment, the more people will have the knowledge to respond to save lives. A study showed that 7% caregivers who received food allergy training reported using an auto-injector for a child in their care compared to 1.3% of caregivers who used an auto-injector without prior training (Wahl, 2015). This emphasizes caregivers who are properly trained on effective epinephrine administration will be more likely

to use an auto-injector. Proper epinephrine auto injector training to patients, caregivers and health care professionals has been shown to facilitate correct auto injector administration (Mehr et al., 2007). However, despite training, treatment is still inadequate. Some believe that training with a needless demo, does not adequately prepare for a real emergency (Gallagher et al., 2011). Another significant difficulty is identifying an anaphylactic reaction due to the variability of signs and symptoms; anaphylaxis can manifest differently in the same person, even when triggered by the same allergen. After a child experiences their first food allergic reaction, the majority of parents want more information on recognizing signs of anaphylactic reaction, treatment, and coping with anxiety (Abdurrahman et al., 2013). However, despite a prescription of an epinephrine auto injector less than a third of parents actually use it (Mehr et al., 2007). Increased morbidity and mortality is prevalent in food allergic individuals who had a lack of education and care with respect to their food allergy (Pumphrey & Gowland, 2007). Nurses are on the forefront in providing detailed, directed education to the allergic individual and their families. Health care providers play the role of anaphylaxis educators, providing training in epinephrine use and life skills necessary to live safely with a food allergy (Coulson & Knibb, 2007).

It has been shown that parents who receive education from a multidisciplinary allergy clinic improves rates of epinephrine use (Kapoor et al., 2004). However, there is inconsistent advice about use of epinephrine. For instance, advice for treatment with generalized urticaria varies based on the health care provider (Sicherer & Simons, 2007). Also, the possibility of an escalating reaction warrants administration of epinephrine. Tailored education and support to meet the needs of the patient and caregivers can reduce anxiety levels and morbidity (Akeson et al., 2007). The Children's Hospital in Winnipeg currently organizes educational sessions on

anaphylaxis and epinephrine auto-injector training (T. Furst, personal communication, October 28, 2014). Despite educational and training sessions like these, parents still fail to use this life-saving medication. Gallagher (2011) states “auto injector training currently offered is often inadequate preparation for an emergency” (p. 869). It is crucial to get a better understanding of parents’ perceptions and beliefs during their child’s anaphylactic reaction so that health care professionals can provide education that addresses the issues that hinder administration of medication. Therefore, with a better understanding, health care providers can educate and provide adequate resources to the caregivers of allergic children to improve quality of life, and teach proper management practices to the food allergic children for the rest of their lives.

Parents are often responsible for managing food allergies in children under 12 years of age. A study showed that mothers of children with food allergies started educating their children about management skills from an early age (Williams et al., 2009). Parents are responsible for developing life skills in their children, and improved knowledge of one’s food allergy can foster better decision making in social surroundings, thereby leading to protective behaviour, decreasing risk, and re-enforcing what actions to take should a problem arise (Rouf et al., 2011; Sampson, Muñoz–Furlong, & Sicherer, 2006). It is important to understand what parent perceptions are, so that they can in turn teach proper coping strategies to their young food allergic children.

The implementation of a food allergy program in Winnipeg only began relatively recently in 2013. This program at the Childrens’ Allergy and Asthma Education Centre, in Winnipeg, Canada was developed in response to the increasing prevalence of food allergies, and a need to educate families was identified as a priority. At a food allergy class, educators ask parents to share their thoughts and feelings when they learnt about their child’s food allergy. Many

thoughts and emotions may overwhelm the family and initial feelings of shock and denial are commonly expressed. Often parents express frustration and anger while others felt sad for their child's future, with comments like "what kind of life will he have?" (N. Ross, personal communication, October.30, 2014). Some parents took the diagnosis as a lifelong prognosis, when in fact almost 90% of milk and egg allergies resolve before school age. This program was designed to address these concerns and help parents deal with this lifelong condition.

Summary

Presently there is no cure for food allergies. Living with food allergies affects all those who care for a child. Health care providers educate caregivers about living with a food allergy and emphasize the importance of treatment. Epinephrine is the only treatment that can reverse symptoms of a reaction, and inaccurate treatment is the primary cause for morbidity and mortality. However, despite the various methods designed to educate caregivers about treatment for anaphylaxis, such as printed material, videos, demonstrations, and one on one or group teaching sessions, caregivers still do not properly treat anaphylactic reactions and epinephrine remains underutilized. There are few quantitative studies that examine barriers to epinephrine use, specifically related to fear, but other thoughts and feelings experienced during a reaction have not been explored. Currently there are no qualitative studies that describe caregivers' beliefs and experiences with epinephrine use. If health care providers have a better understanding of caregiver perspectives, they can provide better support and appropriate education. The information gained from this study can be instrumental for health care providers to implement better teaching strategies.

Chapter 3: Methodology

Every research question requires a systematic approach to discover the answers to the questions posed. This chapter will describe the purpose of this study, and articulate the research question. Furthermore, a detailed explanation of the framework and methodology will be provided.

Study Purpose

The purpose of this project was to explore why auto-injectors are used or avoided during a child's anaphylactic reaction and to describe parents' perceptions and experience with epinephrine use.

Research Question

What are parents' perceptions and lived experiences with EAI use during a child's anaphylactic reaction?

Theoretical Framework

This study will engage participants to reflect on their knowledge and beliefs about epinephrine use during their child's anaphylactic reaction. The Knowledge to Action Cycle (K2A) is a circular, step-by-step guide that will be used as a conceptual framework for this project (Figure 3).

The initial phases of the K2A cycle was a guide to this study. The first two phases include identifying a problem and reviewing the literature on the topic (Graham et al., 2006). For the purpose of this study, it is clear in the available evidence that there is a problem with caregivers administering medication to their child in a timely manner. The third phase consists of adapting the problem to a specific context, and includes a reflection on the value and usefulness of knowledge in a particular situation (Graham et al., 2006).

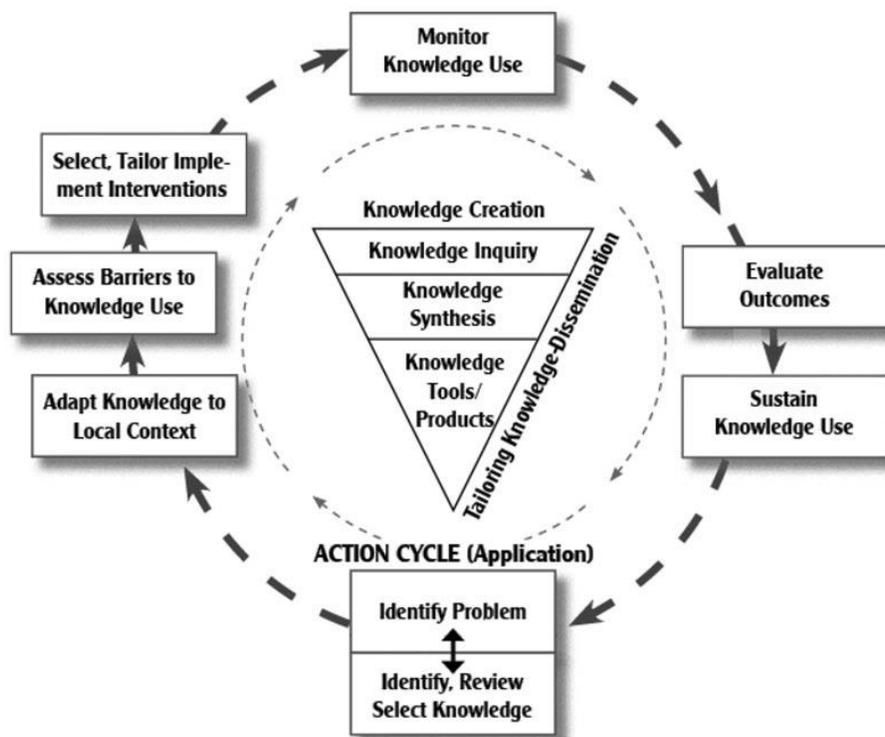


Figure 3. Knowledge to Action cycle (with permission from Graham et al., 2006).

Study Design

Qualitative research is interactive and humanistic, involving the collection of information in a natural environment while being aware of and sensitive to the participant (Creswell, 2003). “Qualitative research has enormous potential to make a distinctive contribution to knowledge about allergy management and to provide insights that quantitative studies cannot” (Gallagher, Worth, & Sheikh, 2009, p. 1117). The qualitative design of phenomenology allows researchers to understand the lived experience of diverse individuals who experience a specific phenomenon by capturing their specific statements during interviews (Creswell, Hanson, Plano, & Morales, 2007). A greater understanding of psychosocial factors can directly impact clinical outcomes by targeting specific interventions (Williams et al., 2009). This phenomenological approach ultimately leads to discovery, and in this process the unexpected may be revealed (Munhall,

2012). Phenomenology incorporates not only the meaning of the words used, but also the undertones of the language and the context of the words used to extract deeper meanings of the study participant's own words and thought processes (Creswell, 1990).

Approval by the University of Manitoba's Education/Nursing Research Ethics Board and Health Science Centre Research Impact Committee were obtained prior to starting the study. Study participants were offered the opportunity to participate in this study to provide their insights into their experience with their child's anaphylactic reaction. This study considered participants within their situated context and related contingencies.

Sample

The following inclusion and exclusion criteria were followed to recruit the participants in this study.

Inclusion criteria. Inclusion criteria were parents and caregivers of children under age 12 with a previous diagnosis of food allergy by a Pediatric Allergist, who have experienced an anaphylactic reaction that required an emergency room visit within the last 24 months. This specific timeframe from last reaction was selected for more reliable recall of the event (Nowak–Wegrzyn, Conover–Walker, & Wood, 2001). They must have previously filled a prescription for an EAI. The caregivers must speak English.

Exclusion criteria. Exclusion criteria included any caregivers who did not speak English, had an anaphylactic reaction more than 24 months ago, or did not have an EAI. Also, caregivers of children living with another major chronic illness were excluded as this may further negatively affect their perception of health or reasons for use of EAI.

Sampling method and recruitment. Creswell explains the importance of selecting the best candidates that have the ability to answer the research question (Creswell, 1994).

Participants were recruited either by a nurse educator from The Children's Allergy & Asthma Education Centre or via posters displayed at the Children's Allergy Clinic. The nurse provided information about the study at the end of parent food allergy education classes. Names and contact information were collected from those who were interested and fit the inclusion criteria or participants were invited to contact the researcher. The researcher confirmed eligibility criteria with all those who were interested.

Sample size and saturation. Qualitative studies make use of iterative methodologies which do not require a predetermined sample size, but rather agree that factors affecting saturation is important (Marshall, Cardon, Poddar, & Fontenot, 2013). When conducting one to one interviews for phenomenological studies, six to 10 participants are typically required (Morse, 2000). Over five months, 12 participants were contacted. One participant did not participate because of lack of time, and another participant's child had a reaction outside the 24-month frame. Therefore 10 participants were recruited, interviews were conducted, and recruitment ceased after the tenth interview as no new themes emerged.

Data Collection and Analysis

This project used steps outlined by Creswell to perform data analysis and interpretation of findings from one-on-one interviews with parents or caregivers of several children living with a life-threatening food allergy (Creswell, 2003). In qualitative research, the interviewer is the instrument or tool that facilitates data collection (Creswell, 1994). Using a purposive sample, a semi-structured, open ended, face-to-face, one-on-one, in person interview was conducted with each participant. The interview is a crucial part of the data collection process, and as such, the preparation for the interview is important. A naturalistic environment, one that is familiar and comfortable to the participant, to conduct an interview is advised (Creswell, 2003). Participants

were allowed to choose a location of their preference; their home or the Children's Allergy & Asthma Education Center as it provides such a naturalistic environment. The center has several classroom style meeting rooms designed for educational sessions for children living with asthma and allergies and participants were familiar with this environment.

Following signing informed consents, demographic data were collected to determine factors that affect epinephrine use. Each participant was asked to tell the story of their child's anaphylactic reaction, outlining their experiences, thoughts and feelings during that critical event. Also, a semi-structured interview guide was developed with a standard set of questions to stimulate participant's natural flow of ideas (see Appendix 2). The interview was audio-recorded. Additional data sources included interviewer's memos and field notes pertaining to the interview process, and medical records. The interviews lasted between 30-70 minutes. After receiving a signed consent from participants, the child's hospital records were accessed to obtain more detailed clinical information regarding clinical symptoms and to confirm the diagnosis of anaphylaxis. If there were questions after review of the hospital chart, a second interview was conducted. This type of data triangulation allowed for a greater depth of clinical understanding and addressed the issue of recall bias.

Data sources included ten transcripts, field notes, and memos along with the child's medical records. Immediately after the interview, reflective memos were dictated and added to the audio recordings. Audio recordings were collected and transcribed verbatim by an independent transcriptionist. Along with the transcription, audio recordings were used to listen for tone, hesitation, and emphasis. Field notes recorded during the interview were used to emphasize significance when data was being analyzed. As a form of verification, random copies

of transcripts were reviewed by another researcher to ensure that there was congruence in theme development.

All data sources were imported into NVivo v11.2 software. Demographic data was entered into NVivo so that codes could be analyzed according to specific variables such as caregiver type, education level or household income.

Data analysis allows the researcher to move beyond the text and into a greater understanding of the meaning behind the text (Creswell, 2003). Initially, a naïve reading was performed to obtain a better appreciation of what the participants were describing (Lindseth & Norberg, 2004). This included reading, and re-reading the transcript multiple times, which also allowed the opportunity to correct any errors that may have been made during transcription. After listening to the audio in tandem with reading the text, each line in the transcript was examined to look for repeating words, phrases or any text that was emphasized by the participant. These repeated words, phrases or ideas were first underlined in the transcript to display importance. After underlining the transcript, codes were assigned that encompassed the *in vivo* terms. This project focused on the descriptive words or phrases that the participant used when talking about their experience. Also, any words introduced during the interview by the interviewer were not considered as part of a code. These prompted words are considered to be part of the interview guide rather than the participants' own words about the phenomenon being studied. It is important to remember that by extracting a word, the meaning may change if taken out of context (Bernard, 1991). Therefore words or phrases that held similar meaning within the context should also be included within their respective code.

Having another researcher reviewing the process ensures trustworthiness of themes and sufficient significant statements from participants (Martins, 2008). An independent researcher

also completed independent analysis on a subset of transcripts to ensure both researchers independently were able to identify significant quotes and subsequent codes.

Ethical Considerations

All potential participants who met the eligibility criteria were equitably recruited. The researcher had no previous health care relationship with potential participants. The Personal Health Information Act guidelines were adhered to at all times to ensure confidentiality. Study participants were assigned a study code and these were used in study files rather than their names. All personal information including names and consent forms were kept secure in a locked cabinet in the researcher's locked office separate from the database. Data was stored in a central encrypted server and housed in the John Buhler Research Centre in Winnipeg, Manitoba. The secure drive had firewalls to secure all information, and allowed access only by authorized, password-protected user accounts. An independent transcriptionist was hired and signed a confidentiality waiver. This ensured all study participant information remained confidential and safe.

All participants were given a thorough explanation about the study. They had the right to refuse participation at any time. It was important to respect and consider the competency and diversity between each participant when consenting, collecting, and interpreting data. Confidentiality of data collected and identification of the participant is, as always, of top priority. Data was collected electronically and stored on a secured, encrypted server, and any access to data by the study investigator was recorded at login.

Chapter 4: Findings

The following chapter will provide the study findings. Excerpts from interviews were taken from the transcripts and pseudonyms were used to respect the confidentiality of the study participants. From data collected, demographic information was compiled and themes were identified.

Demographics

A questionnaire was collected to capture participant's demographics, including age, gender, education level, child's age at diagnosis, types of food allergies, number of reactions, and number of times EAI was used by a participant. Table 1 provides an overview. Twelve individuals were contacted, ten participated (five females) aged 32 to 46 years (mean age 41 years).

Variable	Frequency	
	%	N
Caregiver		
Mother	5	50
Father	5	50
Employment Status		
Employed	8	80
Self-Employed	1	10
Unemployed	1	10
Education		
High School	2	20
Post Secondary Degree	8	80
Household Income		
\$75,000 - \$100,000	3	30
\$100,000 - \$125,000	1	10
\$125,000 - \$150,000	1	10
>\$150,000	5	50

Table 1. Study participant demographics.

Five children were described in this study who were three to ten years of age and had multiple food allergies (see Table 2). Four of the children were diagnosed within the first year of life, and one was diagnosed at age 3.

	$\mu \pm S.D.$	
Child Age	6.3 \pm 2.9	
Number of Allergies	4.6 \pm 2.1	
Number of Anaphylaxis Episodes	4.9 \pm 2.1	
EAI uses	3.2 \pm 1.9	
Variable	Frequency	
	N	%
Age at Diagnosis		
≤ 1 yr	4	80
1 – 5 yr	1	20
Diagnosed by		
Allergist	6	60
Emergency Doctor	2	20
Nurse Practitioner	1	10
Unknown	1	10

Table 2. Child demographics.

The length of time participants lived with their child's food allergy ranged from two to nine years. Every child had filled prescriptions for an EAI and kept it present at all times. Every child experienced an anaphylactic reaction requiring an Emergency Department visit within the last 24 months. Children experienced two to nine anaphylactic episodes in their lifetime. Epinephrine treatment from participants ranged from one to six times. As a form of cross verification, data triangulation from hospital charts was obtained to validate participant's recall.

Themes

Analysis uncovered many codes of emotions and thoughts that participants experienced when a child suffered an anaphylactic reaction which could impact their decision to use an EAI. Figure 4 illustrates the eight main themes that emerged from this study; perception of anaphylaxis, life challenges, isolation, anxiety, hesitation, guilt, influence of health care professionals and lessons learned. This figure represents the external and internal influences on a caregiver's perception. This section will review participants' statements and the themes that emerged from the data.

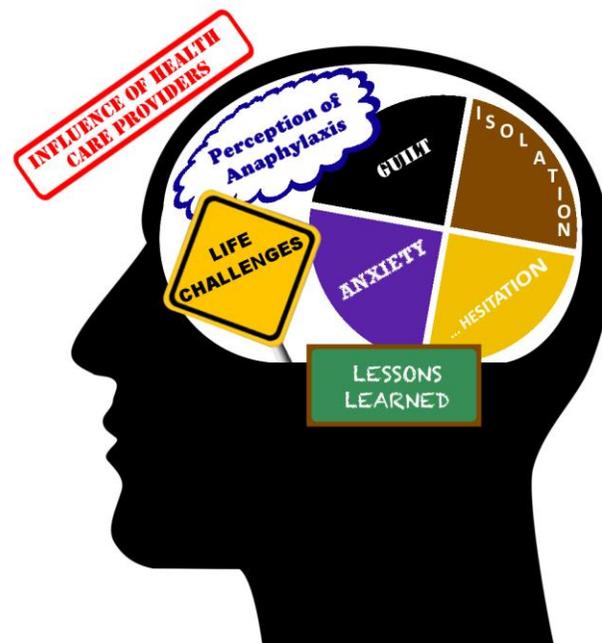


Figure 4. Emerging themes.

Perception of anaphylaxis. The first standard question asked to all participants, was ‘What does the term anaphylaxis mean to you?’ Although the definition exists in dictionaries and medical literature, individuals construct their own meanings based on their experiences that ultimately contribute to their knowledge base. Also, what they have been told about anaphylaxis by others contributes to their understanding.

“Ah, yeah it ah, two, two or more body system reactions and um, you know I, I think we do a great disservice to people with these um, EpiPen videos that show people going into respiratory distress and having red flushed hive-covered faces and dropping to the ground; um, because it doesn't always appear that way. Um, for us, our clue is itchy mouth, instant vomiting, blotchy skin and then demise after that.” (Cathy)

This parent relays their experience with their child's anaphylactic reaction which is very different from how reactions are commonly perceived, and serves as a reminder that all reactions are unique and can manifest differently in the same person, even when triggered by the same allergen.

“But it just means that things are going to go into hyper overdrive and eventually shut down. That's you know, the long and the short of it..... Cause you know it's coming. Like you know you're in a real race. You're in a race for time to make sure that things get fixed properly in a timely fashion.” (Daniel)

The perception that the body's systems "shut down" is used to explain anaphylaxis by this parent. Using an analogy of being in a race stresses how quickly the reaction changes. It is a good example to easily describe how fast anaphylaxis occurs and how quick caregivers must respond, without relying on commonly used medical terms or specific detailed symptoms. These comments reinforce that it is the caregivers who are in a race to save a life.

“Uh, basically life or death, really if I think about it, um, and that it's serious and that you don't take chances. And that people don't understand itlike unless you've seen your child basically starting to die in front of you don't, like they don't get it.” (Janet)

Participants think of an anaphylactic reaction as witnessing death. The idea that people will not be able to understand the severity unless they witness it for themselves shows how influential the experience is on an individual's perception.

Life challenges. Life changed for all study participants immediately after they learned that a child in their care had a food allergy. Many explained how quickly every aspect of their life changed, and the many challenges they encountered or accompanied this medical condition. The obvious and immediate change was avoidance of the suspect allergen. Some participants

explained the challenges associated with avoiding allergens. For instance, a caregiver of a child with dairy allergy expressed the additional burden of sourcing foods that do not contain milk and eggs. Also, it was noted that if the child had multiple food allergies it made avoidance and shopping much more complicated.

“You add one more allergy and that changes what, what the child can eat. Um, but yeah, just that knowledge of, of what you can do. Um, like even like it’s silly but you get a list like this and it’s like how do you bake? Like how do you, how do you even make pancakes? How do you make bread? How do you make; these are things that people don’t necessarily know how to do. And they have to sub out like every ingredient. Like you can’t, you can’t use eggs, you can’t use milk, you can’t use flour. So how do you make; how do you bake anything? How do you, how do you cook anything? Um, even, even references to like cookbooks that work for this kind of extensive lists and that sort of stuff um, would probably be helpful. That was probably the number one challenge we had.” (James)

Society integrates food in all social activities whether they are at family gatherings, meals at restaurants, school, team activities, or celebrations. Interviews revealed the task of constantly checking, and re-checking food labels while grocery shopping became an added burden that families had to face on a daily basis. Sourcing alternative foods is possible, but requires both more work and necessitates more expense.

“Dealing with the high cost of these foods is intense, and we are both middle-income earners. Chris has a very healthy appetite and we’re fearful of puberty. I’ve been meaning to do a cost comparison of staple items, such as vegan margarine at 3.99 vs. regular; soy yogurt is on average \$5 for a large tub and approx. \$8 for an 8-pack of single serving cups (there’s only 2 that are fortified with calcium and this should be legislated). Good grief, what do low income people with allergies do?” (Cathy)

“At 110 bucks it’s like whoa eh, hold on. You know, never mind the ambulance rides...So it’s expensive so people can’t afford that, that epinephrine. It’s expensive. But ah, yeah, that epinephrine, 110 bucks a shot. Some parents are going to be like, whoa, they’ll give it to them the first time but maybe the second time they’ll wait it out a little bit too long maybe or they’ll wait it out, see what happens. At 110 bucks and I think, this past year he used it like 4 or 5 times and you know it adds up right. And they’re good for one year so after a year you’ve got to throw it out.” (Jack)

“I don’t know if people have ah any concern at all about the cost of an EpiPen; ah, I don’t. But I can envision that some people maybe do. Cause even, like even with a drug

plan they're still 20 bucks right? And you know for some people maybe 20 bucks is too much." (James)

These statements by participants relay the fact that not only is it a challenge to vigilantly shop for foods that are allergy safe for their children, but the expense is felt in both the cost of food, medication, and ambulance fees. At approximately \$100 per EAI, even patients who have stable incomes can feel the effects of paying for an auto injector. This is further compounded when they are often advised that they should have one for home, school, backpack and other locations. One participant in this study had a total of seven EAIs (both in-date as well as expired) in the home. Some participants went as far as discussing that travelling is a major challenge that be best avoided. Preparations including filling multiple prescriptions of EAIs, finding accommodations with a kitchen to prepare meals, and plotting out nearby grocery stores and hospitals are necessary.

Isolation. Another significant challenge was a change in relationships within the extended family, friends and other support groups. These challenges had the greatest impact on the quality of life experienced by those living with a food allergy and their families. Isolation was a common theme and it was described in both emotional and physical contexts. The emotional aspect of isolation related to all forms of relationships, whether it involved family, friends, or co-workers. Relations that were strong often seemed to dissipate after learning about a child's food allergy. These dissolving relationships were bidirectional as it not only affected those who did not understand anaphylaxis or even feared the possibility of a reaction, but also relationships were ended by participants who felt that people did not understand food allergies which was a potential source of risk. One participant described his child having an anaphylactic reaction when with a family member and explained that the child will no longer be at that family member's home again.

“The family thing really bothers me because they’re family. I don’t get it. I don’t get that kay, you’re, we’ve told you several times. It happens every single time. And it’s been a little bit of a battle but and now like that you know we’ll, we rarely go there.” (Kris)

This participant felt frustration with his family because they continued to put his child at risk of a reaction and believed that the best action is to avoid visiting their home.

“Um, well it can be lonely. Um, you really find out who your friends are (crying). So you know friends that I had totally been there for just basically vanished the second that Sarah was diagnosed. So because nobody wants their lives to be inconvenienced and food is such a big social aspect. So, things like getting together for play dates or you know all the stuff we used to do before, nobody really wants to do that.” (Emily)

This participant clearly felt isolated. She hoped for support from friends and family whom she had supported in the past, but believed that they were unable to adapt to the necessary dietary changes and cope with the imminent danger and therefore, these friends were not there when she needed them.

“If I had to lose everybody because of what these people in this family, I would say tough shit and I would cope because it’s them. I like, I’ve got to take care of him I think he’s just um, he’s doesn’t, we’re not like him. He, he the things he has; my stomach will hurt if I eat beef so I don’t eat beef. He’ll die. Like, it’ll kill him right? So I tell them straight out. The family thing really bothers me because they’re family. I don’t under[stand], I, I don’t get it. I don’t get that kay, you’re, we’ve told you several times. It happens every single time. ...So if you get pissed and don’t want to hang with me anymore or don’t want to have anything to do with me, I still got my son...I just tell people. I know people are unhappy with me telling them but like I said, I’m like, if you knew me any better, I, I don’t care what people think. Like, like cause you can be mad at me or he could die. And I see; that’s how black and white I see it.” (Kris)

The safety of this participant’s child is the primary concern, regardless if this meant isolating from family members. This parent perceived that other family members failed to understand the gravity of the situation.

“Lack of understanding and support from employers and co-workers: On Jan 26th, after being with Chris in the ER, I returned to work. I was asked (by email) if he was okay, but nobody picked up the phone to ask, or to ask me how I was doing, or perhaps just let me go home. I honestly don’t think they realized how serious it was.” (Cathy)

Feeling a lack of support and understanding from colleagues was associated with this participant's isolation. It was important to her that people in her life appreciate the seriousness of the situation.

“Uh, basically life or death, really if I think about it, um, and that it's serious and that you don't take chances. And that people don't understand it base, either; like unless you've seen your child basically starting to die in front of you don't, like they don't get it. And even now, some of our family doesn't quite get it. So it's also frustrating.” (Janet)

This participant expressed fear when seeing his child suffer a life-threatening reaction, but felt that others who have not witnessed something similar could not truly empathize, thus feeling alone. The frustration becomes evident when one's own family does not understand the implications of this condition.

“they have a table they've set up. Um if you know custodians at all, custodians follow unions like I don't have to do this, I don't have to; again, this guy if he doesn't do it one of the teachers or EA's, they disinfect his table and his chair. But he has a separate table, cause we didn't want him to go sit in some corner or in a like in a back room. Um, so he sits at a table right beside the round table; a like right on to it. And none of the kids touch it.” (Kris)

This participant is comfortable with their child having a separate table for lunch. Although the child is on his own table, it allows the child to be in close to friends. This is an example of when isolation provides a measure of comfort to the caregiver.

Anxiety. Anxiety and fear are parental instincts that intensify when their child has been diagnosed with a food allergy. Participants described the feeling of anxiety as constant. It is present when they are away from their child and even when they are by their side. Some describe that anxiety may improve with time, but on the other hand it can stay for years.

“we're still scared. You know so yeah I, I fear for my son (crying). Um, we question as parents whether he's going to get to be able to do all the things that we want him to be able to do, because of our own fears. And just because of the re, the reality of that, that he needs that extra care or that extra awareness.” (Marie)

These comments evoke the fear of the unknown that this participant faces not just for her son's safety, but also for his future health and wellbeing.

“it’s still a very visceral fear that’s always brooding in the back of your mind. What’s going on at school, what’s going on at school (tapping his pen on the table)? And you can’t let it get in the way of doing your job because you also have, and you, or, you know looking after your other children. But it, it can be tough. Um, wow, (tapping pen) scared. Uh, always alert. Con, like just concerned always; you’re always in a constant state of, of alertness to it. And that, and, and, and fear. Right? Cause I can’t be there 24/7. So it’s, you know, you have to, yeah it’s just, I’ll say fear. I’m not going to lie you know. It, it just is what it is. It’s ah, this nagging background fear that something’s going to happen.” (Daniel)

This illustrates that parents live with the ever-present possibility of a severe reaction, and also the morbidity associated with living in a state of constant uncertainty and anxiety. Many participants in this study emphasized that eating at restaurants or attending social gatherings is anxiety provoking.

“Because like she was, (crying) I’m sorry but she was basically dying in the back of the car and I was sitting there in the back with her trying to like wake her up because she was starting to pass out now. And I was like wiggling her face and like talking and being all animated in front of her.” (Janet)

The traumatic memory relived by this participant casts a stark reminder of the seriousness of this situation, and reminds her of the mortality of her daughter. She expressed what it felt like to live with the fear of a fatal reaction, and also the difficult and painful memories of past reactions.

“Ah (big sigh) like I can see him sitting the truck there; I can see him in the rear-view mirror and that was like a helpless feeling (crying), like I couldn’t help him. And uh, like I knew I had to stay calm and we’d be in the parking lot in like less than a minute but you know that’s a long time when you’re body’s, you know, in trouble (sigh). So, and then he says how his tummy feels, and so how he looks at me and then how, how his tummy feels and everything....He looks like um, so serious at me and he’s ah, it’s just like I can see his soul or something. It’s just he’s telling me like Mom I need help (crying). It can be emotional.” (Tara)

This statement evokes the fear and sense of helplessness that parents experience when faced with their child's reaction. Reactions are unexpected, and not being able to control a situation can result in an overwhelming feeling of dread.

“I know from that first time when we got to the hospital and they were like why didn’t you give the EpiPen? And they were basically like yelling at us. And my own, it was my own fear. It was my fear of hurting my child even though I knew the needle was the right thing. Um, I guess, I think there was even fear of like doing it wrong.” (Marie)

The experience shared by this participant demonstrates both the fear of inaction and the fear of action. This participant was terrified that she may do something that may harm their child, but are also afraid of not being able to do the right thing when the time comes. This is further complicated by the feelings of shame and guilt that caregivers may experience when they feel like others are judging them. Fear and anxiety is pronounced, whether it is from the illness itself, the difficulty managing and treating a reaction, or even fear experienced from the response of health care providers.

“(crying) Cause we’re sad I think that this is happening to him and we don’t want anything bad to happen to him of course or anyone and we really love him so much. And then were all scared because this terrible thing is going on and then this needle is going to hurt too right. And, ah, they’re really good with having needles. And um, I know it will be okay, the needle, but you know why does he have to have more pain now? You know? So, and then he looks at me. He’s really strong and ah, he said “I’m ready Mom.” You know like, you know okay, do it or I say okay we have to do this and he agrees like he’s really good like that. He doesn’t move and, and like I did it.” (Tara)

The fear of what is perceived as inflicting more pain on one’s child is a common theme that participants described. Even when parents are witnessing their child suffering a severe reaction, the thought of giving a needle often seems an overly invasive intervention, despite the fact that they recognize it is necessary. The fact that inaction or hesitation will cause more harm is often blurred by the desire to not cause further pain.

Hesitation. Hesitation was a common reaction when participants doubted themselves because of uncertainty. Often it was confusion about how the child came in contact with the suspect allergen rather than issues regarding acknowledgment of the reaction. Denial, being reluctant to treat and the urge to wait to see what happens was a common response to an anaphylactic reaction.

“I’m assuming it is some kind of defense mechanism or just, this can’t be happening. Right? But ah, maybe just like a minor food allergy but not a life-threatening one. Yeah, cause no one wants to give your kid an EpiPen right?” (Mark)

“Doubt. Self-doubt; do I, am I doing the right thing? Am I over-reacting? Am I under-reacting?...My brain didn’t say get me the EpiPen, then I’ll take him. I’ve been trained, I’ve trained people. Like I mean I used to work in a public, as a public health nurse in the schools. Like, brutal, absolutely brutal but in the moment with the gradual onset that’s not this big, exciting, obvious thing. It’s, ah, it’s human nature sometimes takes over and you’re, I don’t know if it’s denial, if it’s just oh, he’s okay, I’m watching...But it’s like you know what, just, just give it. But I was still thinking really? Really? This is warranted?...I was questioning myself while I’m preparing to give it. And he’s “No, Mommy No!” And I’m shaking, and I’m crying, I’m like, “Sorry Jasper, we have to.” Instant relief of all symptoms...But it was tough to actually pull the trigger and say we’re giving it. Because again I felt that pull to; ah, he’s not that bad yet, let’s wait.” (Cathy)

This participant’s comments serves as a reminder that even in well trained individuals who have experience with anaphylaxis, there is still a hesitation to act, and a sense of downplaying the severity of a situation that can quickly escalate. The inner conflict of self-doubt leading to hesitation is a commonly identified theme among participants. This parent’s response to the uncertainty of acting, and also how others may view their actions serve to illustrate that caregivers are dealing with more than the critical situation of anaphylaxis. They are dealing with thoughts and fears about how to treat-“pulling the trigger”, when to treat, consequences of pulling the trigger (hurting their child further) and what others will think of their actions and the future actions of others. One participant described an EAI as a “horse tranquilizer” because of the size of the cartridge. He described the anxiety associated with using something that large on a

small child. Processing all these various thoughts at a critical moment can contribute to hesitation when EAI use is required.

“Um, I think in my head I knew that with the training that we’d been given, that knowing he had drank his, his number one allergen that we should have given the EpiPen, but it was the fear of “I’m going to make this worse for my child.” Like he’s already dealing with the struggling; he was having trouble breathing, but you know, and he was, his face was swelling. Um and it was the, well we just need to get him to the hospital because I don’t want to hurt him more. And I think I kept thinking in my head, “Well if I see that he’s having trouble breathing, then I’ll give him the EpiPen. But he’s still breathing okay right now so then he doesn’t need the EpiPen.” (Marie)

This participant’s experience demonstrates that how even in the best of circumstances, when caregivers are vigilant and know the appropriate course of action, there is even then still a moment of hesitation. There seems to always be an undercurrent of reluctance to give an epinephrine injection, partly because of the fear of giving an intervention that may be perceived to be painful, administering the EAI will worsen the condition and perhaps partly due to the underlying hope that the reaction will not escalate.

“I’m thinking, well that’s why I stopped and pulled over right away, just to see how distressed was he. Because, did I have, at the moment, you’re never, cause the, the crazy thing about this is, is like; how bad is this really going to be? How, because you keep thinking; God it can’t be! No! And you know; I knew in my heart that this was, he was having a reaction. But, he’s covered in barf, I’ve got another, his younger brother is crying and worried beside him and I’m blocking traffic. It’s like a whole, a whole kaleidoscope of, of, of, ah stressors; just boom, boom, boom, boom, boom, boom, boom. So I guess it was, I guess in a way I took a calculated risk in whipping him into the school instead of just jamming the EpiPen in his, in his leg at that, at right at that moment.” (Daniel)

These statements reveal the multiple sources of stress, anxiety and doubt that a caregiver feels when faced with an anaphylactic reaction. Even when they know that a reaction is occurring, there continues to be a reluctance to proceed with the use of epinephrine. In this case, the participant admits that he took a calculated risk by not administering the epinephrine. Once again it is evident that hesitation during a stressful moment leads to delay in administration of

epinephrine, even when the caregiver is well aware of the correct course of action, in part due to situational stressors or a “kaleidoscope of stressors”.

Guilt. A sense of guilt stemmed from many sources. One reason for experiencing guilt was directly due to not treating the reaction. Participants expressed other reasons for feeling guilt, and often identified it was due to the way they had decided to live life and care for their child with a food allergy.

“the words we use are probably pretty offensive and probably my kids should go for counselling because he probably feels like some, some kind of leper because we’re always talking about contamination and cross-contamination.” (Cathy)

This participant explains how guilty feelings arise with common terms used to keep a child with a food allergy safe, such as “contamination”. The implications of using terms like contamination (often associated with connotations such as harmful, unclean) make this parent think that her child will feel different from other children.

“Guilt! That we could have, especially once they gave him the EpiPen and we saw how quickly he got better; that I was like I just caused him to have a worse reaction by waiting because I was scared to give a needle, you know (crying).” (Marie)

This participant’s perception of guilt revolves around the delayed use of the EAI for fear of having to give a needle. This guilt is magnified by how quickly their child improved upon treatment with epinephrine, and further reflects the guilt of what the parent perceives as unnecessary suffering, which could have been avoided if only they had acted sooner.

“I should have given it. But then I still didn’t give it cause I’m almost there. And I’m just like oh crap this is serious! Like I mean when I looked at him standing naked after the tub, in the bathroom, his skin was mottled. Like that’s a circulatory issue (nervous laughing). I’ve worked emerge, like I just felt such shame and I felt so stupid. And like me fluffing it off, or you know watch and, watchful waiting, or, you know, you know observation is going to kill him one day and I’m trying to snap out of that.” (Cathy)

Feelings of guilt are identified when this participant reflected upon her experiences and identified situations when she knows her management should have been different. This is another

example of a parent feeling guilt for not acting quickly. Anaphylaxis is one illness in which 'watchful waiting' is a potentially life-threatening decision, and this parent's resultant guilt stems at least in part from following such a course of action.

“Should we well, if we would have injected him, that’s what we were told if we were injected him he would have got in right away. But we didn’t inject him. But stupid parents, we didn’t at the time, we didn’t know what was really going on with him.” (Kris)

“I think I was seriously thinking that like I could lose my son! He could die! Like, this isn’t right. And I had, I still had the EpiPen. It was still around him. It was on, on his belt.” (Marie)

The realization that there is a potential for a child’s death is something that cannot be simply put into words, and at times is inconceivable. This participant felt guilt by knowing that the medication was on hand but did not use it.

Influence of health care professionals. Caregivers are reliant on health care providers who are medically trained to manage and treat patients with food allergies. We trust them because of their profession, and rely on them to be proficient and current on the most up to date knowledge and principles. We leave our health, and the health of those we love in their hands. But how do their actions or their reactions affect us?

“I know from that first time when we got to the hospital and they were like why didn’t you give the EpiPen? And they were basically like yelling at us. And my own, it was my own fear. It was my fear of hurting my child even though I knew the needle was the right thing. Um, I guess, I think there was even fear of like doing it wrong.” (Marie)

This participant describes the response from emergency staff, specifically relating to the reaction encountered when healthcare providers questioned why an EAI was not administered. This participant relates feeling berated by medical staff due to her lack of EAI use. This situation illustrates that not only do parents rely upon healthcare professionals to treat their child’s medical needs, but parents also perceive them as a source of authority, and how health care providers react to patients and their families can provide a lasting impression.

“But then when they don’t give it either, you know you can say okay because they’re in the hospital they can always intubate and start IVs and do all these wonderful things. But hello? Like if you really want to reinforce proper parental management in the community, you got to role model (snaps her fingers) it in the hospital too. So I was; that kind of pissed me off.” (Cathy)

When a participant encounters a situation when health care providers do not provide what is known to be the standard of care for an anaphylactic reaction, it raises doubts in their mind about the competency of the health care provider and the appropriateness of EAI use. The action of a health care professional not administering an EAI undermines the teaching that caregivers have received regarding prompt epinephrine use. Essentially this situation raises the question in the parent’s mind ‘if the professionals don’t use epinephrine in an emergency, then why should I?’

“So I called her pediatrician and I said, look this is what happening. She started to wheeze and um, he said well just put the phone up to her, up to her mouth so I can kind of hear her breathe. And she wasn’t wheezing at that time. And he says; he told me that um, it likely was a reaction but basically wait until she was having trouble breathing or if she was turning blue before I called 911. And so I thought okay, that’s what I’m going to do. She was getting hives and you know, whatever, but she never really had the breathing issue again. Um, I know in retrospect, 911 should have been called and I actually harbour a lot of anger to him (crying) for that because I remember like after an hour I even put her down for a nap. And it was; just we’re lucky we didn’t lose her. So (quite emotional) that one was the first big one.” (Emily)

This participant relates an experience where she was specifically told by a health care provider of when to do something that she retrospectively realizes was not consistent with the standard of care for an anaphylactic reaction. This resulted in doubt and mistrust of health care professionals who are supposed to be experts in the treatment of her child’s illness, and can result in becoming a barrier to future care.

“we had a reaction in Alberta and the hospital is completely different than here. I mean they were like, well she can still breathe so why are you even here? And we’re like she has hives this big on her! She’s got four inch hives on her and she’s coughing all the time. Like it’s, it’s you know with, with a diagnosis of anaphylaxis you would treat this as anaphylaxis. But they were nah it’s fine; go away. You know like thanks! (laughs), um so

yeah and I mean and you can see that ah in the States they recommend ah, antihistamines all the time but they don't help so." (James)

The experience illustrated above is another example of when a patient encountering a health care provider was given advice that was incorrect and contrary to what they were taught. There are health care providers who take initiative to teach and educate caregivers on proper management and treatment of anaphylaxis, and therefore it is disconcerting to encounter other health care providers who disseminate incorrect information and treatment. As a result, this participant's statement implies because of the inconsistency, they have less trust in the health care system.

"Um, and unfortunately when we got to the hospital, even though we walked in and said, we came to Children's Emerg and said 'like my son is having an anaphylactic reaction, he drank milk, we know he's allergic.' They didn't understand or they didn't proceed. So they checked him, they monitored him but they left us to stay in the waiting room. Well, it progressively got worse and worse within minutes obviously. He was ending up, he couldn't even swallow, he was just drooling all over me. And um, then we finally were, like wait a sec, something, like this isn't okay." (Marie)

"We didn't move far away so they can, I don't know, we kept you like, should we do something? But stupid parents, we didn't at the time, we didn't know what was really going on with him. he was drooling and coughing and so I lost my mind and freaked out on them and said like I don't know. Like I need help! And so then some doctor in the back heard and he came out and, and then they started taking care of him and they um, they injected him." (Kris)

This participant relates a distressing experience where their son was left without treatment in a waiting room while having an anaphylactic reaction. When patients or caregivers for patients who live with food allergies seek emergent care, they expect emergent, appropriate treatment. When this is not provided, families are left frustrated and confused with a potential life-threatening situation.

"And I found that when we were diagnosed, we weren't really given any information. So somebody who's not educated I, I think that it's, it's actually, it's dangerous; like you're not provided with lists of all the other names that all these foods come under. You know you're not provided with um, pictures of what like the reactions look like." (Emily)

This participant trusted the health care professional to provide them with the necessary education and training pertaining to dealing with an anaphylactic reaction. When this information is not provided, the patient is left feeling confused, anxious, and alone.

Lessons learned. The best advice might be from someone who has experienced a life-threatening reaction. This real world advice has both the weight of personal experience and may be more directly relatable to an individual in the same circumstance, in this case advice from a caregiver to a caregiver. This type of lesson or education may prove more effective than artificially constructed or simulated examples from other health care providers who do not share the same life experience. Health care providers may be able to superficially empathize with caregiver situations but cannot empathize in the same way as another caregiver.

“I think what’s completely under estimated is the mental health component. The anxiety, the stress, the, for a school age kid not fitting in. Everything we do in society you quickly learn is very much focused around food. Classroom celebrations, pizza parties, fun lunch, Halloween, Christmas, Valentine’s Day, Easter bunny, the whole nine yards. It’s, it’s a logistical expensive, logistical nightmare trying to keep pace to make your kid feel left, less left out. But invariably they know they’re different. They do stick out.” (Cathy)

This parent relates that they have learnt that not only must one deal with the direct health implications of living with a food allergy, but the numerous psychosocial aspects as well, which includes re-evaluating how a child and their family interacts with others in typical daily social interactions and negotiate inclusiveness

“I have documented most of Sarah’s reactions; I put together a book for her daycare when we had to put her into day care to say this is what all these things look like on the different sites of her body. This is what you’re looking for (taps the table). So that they know because they take it and they don’t understand. And they, they told us that they learned more from us than they did URIS. Because they, they hear okay well hives but nobody really knows what hives look like. So you know having, having a resource like that I think would have been really helpful for me to also have somebody tell me what it would be like to; the importance of documenting everything.” (Emily)

This family copes with lifestyle changes by becoming proactive and advocating for their child. By providing detailed information on their child's health and possible signs of reaction, they empower themselves and thus are better able to deal with the challenges they must face on a daily basis.

“always think anaphylaxis even if there’s been a long delay between a potential exposure, even if you haven’t seen it. Because if you don’t see it your tendency is to figure out what’s wrong and I’ve caught, been caught in that trap so many times where you’re trying to figure out was there an exposure? What happened? Rather than just recognize the symptoms and re, respond appropriately. Rather than trying to figure it out. But I think that’s, I don’t know if that’s human nature or if that the nursing thing, but you gotta just respond and ask questions later.” (Cathy)

The lessons learned from this parent's experience with their child's food allergy has allowed them to reflect upon and evaluate their initial response and coping skills. Whereas it may be second nature to try to answer the question 'why is my child having a reaction now', experience has taught this participant that the ‘why’ really is not the important question at the time. Rather the thought process must be 'my child is having a reaction now and I need to treat it.'

“Um, so I don’t know if that fear is out there. It seems, it seems a little crazy that, um, it almost seems crazy that to me that you even need a prescription for them. Like I don’t know if they can be abused at all but it’s just like who gets an EpiPen that doesn’t need one? You know, um yeah no, as far as ah, as ways to get over the fear for a parent, I think one way would be just to give them EpiPens on themselves (laughs).” (James)

I think they’re scared that they’re going to hurt the child by jamming a needle in them. Or they’re scared that they’re going to get in trouble for doing something that wasn’t necessary, right? So people’s fears need to be allayed, that you’re not going to get, you won’t be held accountable for the cost of an epi, because some people worry about things like this. Or that you’ve done something medically wrong to the child or something. Just give it.” (Daniel)

Parents relate that one of the key features of coping with the lifestyle changes that come with living with a food allergy is learning to get over the fear of using an epinephrine auto injector. Coping in this case may mean finding ways to mitigate the costs of treatment, and also

exploring ways to make caregivers more comfortable with the safety of administering an auto injector.

“I don’t think we realized the force you needed to push with. Which is you know, you get a trainer and it’s super loose and um but the big EpiPens you have to push a bit harder. Like the real ones.” (James)

This parent relates real world experience with using an EAI. Specifically, they relate how using an actual device is not the same as using a trainer, and one way of coping may include becoming more comfortable by practicing with an actual device.

“I think realistic, if we’re gonna do videos, like you tube videos or whatever, realistic scenarios of like a range of situations and presentations. That it’s not just this classical guy choking in a field with a red face, um because of a bee sting or whatever. Um, but to, to, put forward the notion that there are a whole slew of food allergies and mixed and that trace amounts can cause an anaphylactic reaction and that it’s not always a big show. And it can be a gradual presentation; a very slow moving start where you kind of have to be observant and take note and go and start adding it together and go, okay here we go. And maybe even hear from some kids that have had it to say you know what, it wasn’t that bad. I felt instantly better. It really didn’t hurt that much.” (Cathy)

“I think they probably do need to hear it from other parents who have been there. Cause it’s one thing to hear a nurse say it’s no problem or a doctor say just give it, but it’s, it’s also um, what else are you going to say right? But how about here’s someone who’s lived it? And whose daughter is you know even, this is going to sound terrible and you probably can’t do this but, like even like here’s a little girl, she’s fine; she’s had 10 EpiPens. Right and she’s probably fine because she’s had 10 EpiPens. Cause if she didn’t she might not be standing there.” (James)

“Well, I think if they tell more stories about people who don’t trust their instincts. You know, don’t question yourself, you know, the, the denial stuff. If they hear more people that you know who also feel that way but in hind sight after looking at it you’ve got to trust your instincts and do it. Like don’t, don’t waiver right? Ah, that would be helpful too. Cause that seems pretty common with most people that I hear and I say, “Well did you give it to them?” They’re like, “No.” You know like we just called the ambulance. And so it’s like you know, that takes time. Right so. Ah yeah, maybe sharing those stories would be helpful.” (Mark)

These parents relate what they would like to see in the context of an educational tool for anaphylaxis and food allergies. They relate that they would appreciate seeing real world examples of reactions and hearing from those who have had the experience of suffering from an

anaphylactic reaction, using an EAI and even the subjective experience of those who have been given epinephrine to treat an anaphylactic reaction. In addition, sharing experiences of others who have gone through the common feelings of fear, doubt and helplessness when they have been faced with having to treat a loved one suffering a reaction, would be helpful. The general consensus is an educational video which includes real world experience and that explores some of the common barriers that families with food allergies are faced with would be a helpful resource.

Responses to Caring for a Child with Food Allergy

Participants experienced a wide range of responses when it comes to caring for a child with food allergies. Table 3 lists the diverse emotions experienced by parents displayed by gender and the number of times statements were captured into the specific emotion category.

Emotions	# of Males (# of statements)	# of Females (# of statements)
Anger	3 (7)	2 (5)
Anxiety	3 (7)	5 (9)
Cautious	2 (3)	4 (11)
Confused	3 (3)	2 (3)
Disbelief	4 (18)	2 (6)
Fear	4 (9)	5 (16)
Frustration	4 (13)	2 (12)
Guilt	4 (7)	2 (14)
Helplessness	2 (4)	3 (6)
Sadness	1 (1)	5 (12)
Uncertainty	4 (9)	4 (27)

Table 3. Emotions by gender.

Chapter 5: Discussion

The main themes are key points for discussion. This section discusses the pertinent ideas and themes that have been identified in the interviews and relates this study's findings to the current literature.

Educational Information

Education after a diagnosis. The findings of this study identified that participants recognized that information provided about food allergies after diagnosis is inadequate. It is known that anxiety increases in caregivers who do not obtain information when their child is diagnosed (Mandell, Curtis, Gold, & Hardie, 2005). This is similar to another study of parents whom not only identified a lack of information provided after their child was diagnosed with a food allergy, but also acknowledged a long referral wait time (Abdurrahman et al., 2013). There must be a systematic approach for one to navigate the medical system at the time of diagnosis. This should apply both to the treatment plan that health care providers follow and also the expectation of what parents should do after diagnosis. Currently when a child has an anaphylactic reaction and is seen in the Emergency Department, they should be discharged with an EAI and told to avoid the suspect allergen. The child's Emergency Department note is then sent to their pediatrician or family physician, who should follow up with the patient, ideally within a week. The physician then decides if a referral to an Allergist is warranted. The Allergist takes a complete history and conducts allergy tests before referring the patient and family for food allergy education classes. There are many steps and often significant time required to reach the education portion of the process, which may not always lead to education from credible resources. In Winnipeg, the wait time to see a Pediatric Allergist may be from one to four months (S. Paczkoski, personal communication, July.4, 2016). In the meantime, patients are

often left on their own to search for educational material, thereby resulting in increased anxiety and the increased potential for misinformation. However, there is no need to wait for an Allergist to refer a patient for food allergy classes. This can be done in the Emergency Department, when EAI teaching should also be done by a physician, nurse, pharmacist, physician assistant or another appropriately trained health care provider.

Campbell (2008) conducted a study that reviewed all patients who presented to the Emergency Department with anaphylaxis over a defined time period and identified only 37% of patients were discharged with a prescription for an EAI and only 31% were referred to an allergist before discharge (Campbell et al., 2008). Our chart review revealed that all patients who used their EAI at home prior to arrival at the Emergency Department were left without a prescription for a replacement EAI. These individuals may be without an EAI until they are able to see their family physician, pediatrician or Allergist to receive another prescription.

Reasons for low rates of prescription and referrals to an allergist may be due to lack of documentation and a failure to diagnose anaphylaxis. Although there are many tools used to define the criteria of anaphylaxis (see Figure. 2), this may not always be followed. For instance, our review of one particular hospital chart of an Emergency Department admission identified a reaction caused by a known allergen and the diagnosis made was “allergic reaction” and not “anaphylaxis”. This admission included signs and symptoms consistent with anaphylaxis, but since the signs and symptoms were not seen as critical (hives and abdominal pain) and was not treated with epinephrine, it was not diagnosed as anaphylaxis. Physicians might think that anaphylaxis must have respiratory and cardiovascular involvement (Campbell et al., 2008), but based on widely circulated criteria and definitions, this is not the case.

The lack of a diagnosis of anaphylaxis may prevent the process that is needed for this

family to receive referral to an Allergist and eventually receive formal allergy education. Despite patients and caregivers receiving education in the process that currently exists, families identified that lengthy waiting times contribute to increased anxiety, and time without education may lead to subsequent reactions. Based on the 5 hospital charts reviewed, children are kept for observation for six hours after a diagnosis of anaphylaxis. Although, this is a stressful time for patients and caregivers, this is an ideal time for initiation of new or review of past education. A possible solution would include time in the Emergency Department with a nurse educator to provide credible information or resources that the family can access during their wait to see their doctor or Allergist.

Educational methods. With the rise in food allergy prevalence, emphasis on skills and knowledge to safely manage food allergies and education for caregivers is paramount. However, caregiver time constraints and limited qualified food allergy educators may make methods of disseminating information, such as classroom education or one to one teaching sessions a challenge (Lanser, Covar, & Bird, 2016). Therefore establishing alternative methods for effective education using credible sources is a priority. Lanser (2016) conducted focus groups to assess the needs of caregivers managing food allergy and found that learning about food allergies from other families was important. Social supports that have a positive influence on caregivers may include sharing feelings and management experiences from others who have a child with food allergy (Williams & Hankey, 2015). The participants in this study also identified the need for videos describing the lived experiences of others and relayed the benefits from hearing stories and experiences with anaphylaxis from other caregivers. Haigh and Hardy (2010) stated “the importance of storytelling as the foundation of human experience cannot be overestimated” (p. 1) and can be used as an educational strategy. Multiple views or narratives can enhance formal

education by adding diversity and sharing realities. Educational strategies aimed at reducing fear and anxiety in caregivers and thereby increasing self-efficacy, will allow for prompt treatment with an EAI (Simons, 2006). This will also help other caregivers feel less isolated, and will help to prepare them for future challenges that they may face. One study identified parents of children living with a food allergy who needed more information on coping strategies (Abdurrahman et al., 2013). Encouragement and support have been shown to help coping, management and quality of life associated with food allergies (Knibb, Barnes, & Stalker, 2015). One study participant stated that it would be helpful for others to see an actual reaction. Clearly such a demonstration would not be ethical, but hearing another parent describe symptoms and recount the timeline of their child's reaction can provide real life insight. Firsthand experiences, watching emotions and hearing a parent's testimony can be influential to transform behaviour. A video could capture all these aspects and would be a powerful teaching tool for caregivers of a newly diagnosed child.

Emotional Impact

Today, medicine is increasingly concentrating on the importance of quality of life as much as on health outcomes (Ravid et al., 2015). Participants described that every aspect of their life changed after their child was diagnosed with a food allergy, and social activities are limited. These findings were congruent with a previous study that identified parents of children with food allergies found social activities outside the home more stressful than remaining at home (Warren et al., 2015b). Intense emotions experienced during and surrounding a reaction are not only experienced by caregivers, but become part of the child's life as well.

Length of time living with food allergies. One might think that the longer a family lives with a food allergy, lifestyle choices and management become a learned behaviour. A study suggested that the longer one lives with a child with food allergies, the burden of living with the

food allergy decreases (Williams & Hankey, 2015). The reduced burden may be due to finding allergen safe foods at groceries or restaurants, and even the child gaining awareness and responsibility of their allergy. Although this seems intuitive, this study found that the burden and emotions associated with a reaction are still present several years after diagnosis. All participants shared and displayed anxiety with their child's possible future reactions, despite the length of time they have been living with the allergy. One study showed that the longer the time since diagnosis, the more confident children and caregivers become (Knibb et al., 2015). Based on the study findings, all participants still indicated isolation, anxiety and fear when talking about life with their child. It is possible that over time, families learn to better cope with this medical condition, but these emotions still exist. Another study showed that the longer one lives with an allergy, the higher the psychosocial impact of food allergies on a child's development and family activities (LeBovidge et al., 2006).

Responses to caring for a child with a food allergy. When reviewing the gender by emotion results (Table 2), considering that this was not intended to be a quantitative data collection, it can be generalized that amongst males and females, the same emotions were experienced. Two outliers can be noted however. It seems that female participants make more references to being cautious and sad, and male participants display disbelief more commonly than do females in the study. While this information is not intended to draw any specific conclusion, it certainly is an interesting observation, and perhaps could guide future studies to determine what if any significance lay in the areas of gender and different experienced emotions.

Life with multiple food allergies. Participants in this study spoke about caring for children with multiple food allergies and stated that life becomes more difficult with each food allergy. Every specific food allergy adds to the list of foods that must be avoided and therefore

limits food selection. This finding echoes other studies that suggest parents of children with multiple allergies have significantly more anxiety (LeBovidge et al., 2006). One participant described that it is not only food that the household needs to avoid, but also nonfood items in the home. She indicated that many creams and lotions contain food products in the ingredients. For instance, wheat proteins can be found in cosmetics (Laurière et al., 2006). This is another aspect of food allergy that can be easily overlooked as one may not think of checking labels of nonfood items. One study identified egg and milk proteins in medications and even inside the coating of rubber gloves (Anibarro, Seoane, & Mugica, 2007). When considering specific food allergens, one study showed that parents of children with egg or milk food allergies had significantly lower quality of life compared to parents of children with peanut or tree nut allergies (Warren et al., 2015b). Participants in this study echoed these sentiments and explained that avoidance of peanut and tree nuts is perceived to be relatively easy, compared to egg and milk as these are common ingredients in many foods. Participants also stated that they felt that peanut and tree nut allergies are more recognized by society as life-threatening, compared to other food allergens.

Emotions experienced when using an EAI. Many parents recalled the multiple signs and symptoms of anaphylaxis experienced by their child, and they described the helplessness they felt as they witnessed their child's suffering. Despite having an EAI present, almost all parents expressed concern with administering a needle to their child, as they perceived that it would contribute to their child's pain when they are already. It is important for health care providers to inform caregivers that the instantaneous discomfort of a needle will improve and in fact stop the reaction from progressing. It should be reinforced that by having an EAI accessible at all times, they may no longer feel helpless, but rather feel empowered that they have the medication to stop their child's suffering.

The size of the needle was another component that was emphasized particularly by fathers. If one assumes that the needle is the size of the cartridge, then they would certainly assume that the injection would cause significant pain and discomfort. The EAI EpiPen that is commercially available in Canada has a needle length ranging between of 1.3 – 1.6 cm and gauge of 22 (Song, Nelson, Chang, Engler, & Chowdhury, 2005). Health care providers should describe the length of the needle found in EAIs, so that caregivers understand it is similar to the needle size used for routine immunizations.

One study demonstrated that parents who are health care professionals are more confident with using an EAI compared to other parents (Baerg et al., 2014). Even if a parent is a health care provider, it does not necessarily mean that they will use an EAI. In this study, one of the parents who is a health care professional described doubting her child's reaction, hesitating and feeling guilty because of not using the EAI. This participant went as far as to say that having a health care background created more stress for her. She described not wanting to administer an EAI, just in case her child develops severe adverse effects from the epinephrine that she is theoretically aware of because of her health training.

Influence of caregivers. Parents and caregivers are role models for children, and they learn from our actions. It is known that parental attitudes can influence the wellbeing of other caregivers, including their children (Warren et al., 2015b). A study showed that mothers had more anxiety than fathers and went as far as to rate their child's anxiety higher than the child's own rating (King et al., 2009). In another example, a study on food allergy showed that maternal anxiety is associated with adolescent distress, possibly due to children learning from parental behaviour (LeBovidge, Strauch, Kalish, & Schneider, 2009). Health care providers need to explain to caregivers that it is understandable to feel anxiety, but their child can learn to mimic

behaviours that can be unhealthy. Hearing from parents about their experiences, it is evident that some parents are exhibiting these anxious behaviours as well. Some participants described no longer visiting the homes of people that may put their child at risk of a reaction. Avoiding activities strengthen anxious behaviours (Rapee, Wignall, Spence, Lyneham, & Cobham, 2008). Unintentionally, parents pass on their anxious behaviour to their children, who then believe that these behaviours are positive traits (Wilson & Lyons, 2013). Then these children may subsequently learn and develop traits of anxiety. These displays of anxious behaviours can affect a child's relationships, school functioning and quality of life. It has been shown that children who are anxious often have fewer friends compared to children who do not experience anxiety, and this contributes to increased loneliness and reduced peer support (Rapee et al., 2008). Untreated anxiety in children can predict depression later in life (Wilson & Lyons, 2013). However, there are several coping strategies for caregivers to use to help reduce anxiety in a child living with food allergies. Health care providers must encourage caregivers to seek help if they notice their child is becoming anxious, or if the caregiver themselves are anxious. It is important that health care professionals understand the psychological effects associated with living and caring for a child with food allergies, and if necessary, referrals to mental health practitioners should be supported (Roy & Roberts, 2011).

Health Care Professionals

It is important for health care providers to educate parents and caregivers of the many possible signs and symptoms of anaphylaxis and how to treat it, but what tends to be disregarded, is that life is complicated and anaphylaxis and subsequent reactions can occur at any given moment.

Challenges of daily life. Reactions occur when parents least expect them, when caregivers are multitasking and their minds are preoccupied with typical daily life responsibilities. One participant explained a situation when she was driving over a bridge in rush hour traffic with both her children in the backseat of her car. The children were hot, tired and hungry. To alleviate some of the issues, she passed a snack “that may contain nuts” to her children. Instantly her child complained of allergic symptoms. She was stuck in traffic with nowhere to move, and the EAI in the backseat with the child. Everyone in the car panicked and started crying. She could see a parking lot a block ahead, but could not get there. She knew cellphones are illegal while driving, but she dialed 911 anyway. She heard the ambulance while pulling into the parking lot. Health care providers need to realize that when parents present to emergency with their child, they are often concerned and anxious.

Interactions with health care providers. The ways in which hospital staff interacts with caregivers can impact their experience and affect their future actions. Studies have shown that patient satisfaction with Emergency Department experiences are dependent on hospital staff (Olthuis et al., 2014). A hospital emergency staff member described an event in which the parents of a food allergic child presented to the Emergency Department with their child having an anaphylactic reaction while carrying an unused EAI in hand (apparently these types of events are occurring more frequently). On this occasion, the triage nurse immediately made the parent use their EAI on their child. The nurse may have wanted to reinforce previous education by treating the reaction with an EAI, and thereby helping parents overcome their fear in a safe environment. Although the hospital stocks vials of epinephrine and could easily administer the medication, making the parents use their EAI may give them the experience and confidence to do it again. However, this action does not consider the financial aspect of purchasing a replacement.

In attempts to educate and reinforce the correct steps for caregivers, the nurse may not have considered the financial situation of the parents. Also, one must consider if telling a parent to provide self-directed care in the Emergency Department defeats the purpose of them attending the Emergency Department in the first place. What action is best for the family?

Communication and information in a paediatric emergency department are important to parents and their experience (Byczkowski et al., 2013). Parents have stated that kindness, and clear communication of health care providers can positively impact an Emergency Department visit (Nicholas et al., 2016). The response from health care professionals, and the way it is delivered, has a direct effect on caregivers. Caregivers go to Emergency Departments when they need help. These are times when emotions are extreme, and although comments may be made with the intention to teach or reinforce, the effect can be stressful. One family explained that they were yelled at for not using an EAI, and this made them feel guilty and ashamed. It has been shown that negative interactions, such as insensitivity or conflict, have a greater impact on caregivers of children with a food allergy compared to positive social supports (Williams & Hankey, 2015). This suggests that even if a caregiver has strong supports, an insensitive interaction with a health care professional could be detrimental to the caregiver and their overall ability to cope.

One participant described a situation where she witnessed her child's anaphylactic reaction and relied on a telephone call with the child's physician. If there is a need to contact a physician urgently via phone, then there is likely a need to use the EAI and go to the Emergency Department. Intuition and trust were important instincts recognized by caregivers when it comes to caregivers' response to anaphylaxis. Some went on to suggest that as parents, you know your child better than any other person. Health care providers need to instil faith and courage during

training to increase self-efficacy. One would be concerned that when a patient or their family feels diminished by a health care provider, it may strain the therapeutic relationship, and this in turn may lead to delays in seeking care in the future, by avoiding another potentially negative experience. Reminding caregivers that it is normal to doubt oneself can be helpful, as can relaying that anxiety and hesitation are common responses. It should be constantly reinforced that there are no negative consequences to using an EAI.

Inconsistent advice. This study has identified parents' experiences of inconsistent messages from health care professionals. If health care providers teach caregivers the importance of a life-saving medication, this message and action should be consistent with health care providers across all spectrums and points of interaction. The first emergency medicine indicated in anaphylaxis is prompt administration of epinephrine. Health care providers teach and train caregivers to administer intramuscular epinephrine at the first sign of anaphylaxis. A caregiver described sentiments of not wanting to hurt her child more (in addition to the signs and symptoms already caused by the reaction) by giving a needle. If caregivers see that this life-saving medication is not being used by Paramedics or in the Emergency Department, this creates doubt. Why should caregivers use a needle on their child (causing pain to their loved one) when the health care providers do not use it? Another example of a discrepancy pertains to expired EAIs and the advice given from health care providers to patients and caregivers. It is known that the bioavailability of the epinephrine after the expiry date is significantly less, and correlates to the length of time passed after the expiry date (Simons, Gu, & Simons, 2000). However, one study identified health care professionals who stated that expired EAIs are still acceptable to treat a reaction once the medication does not appear cloudy (Money, Barnett, Kuljis, & Lucas, 2013). This may lead to patients and caregivers not refilling their EAI prescription until the expired EAI

becomes discoloured. This is concerning, as it is possible that during a stressful situation, one may reach for and treat an anaphylactic reaction with an expired EAI.

Knowledge to Action Cycle and Results of this Study

With the wealth of research available, it is important to be able to use this information in a practical manner. The disconnect between evidence based medicine and actual practice can present a significant barrier to effective health care (Cochrane et al., 2007). The Canadian Institutes of Health Research (CIHR) defines knowledge translation as "a dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of populations, provide more effective health services and products and strengthen the health care system" (CIHR, 2000). A research study is able to provide better information when it is interpretative within the structure of a previously validated theoretical framework.

Graham (2006) states that, "the focus of K2A is to ultimately enhance health status" (p. 18). The knowledge to action cycle was developed to help researchers bring their findings into practice by providing researchers with a structure to follow based on evidence already identified (Ilott, Gerrish, Laker, & Bray, 2013). The K2A framework acknowledges that the whole cycle contributes to continuing education in health care through the interactions of the stakeholders (Graham et al., 2006). Within this framework, this study identifies both caregivers and healthcare providers as stakeholders. The K2A framework is dynamic with constant interaction between the center triangle, representing knowledge creation and dissemination, and its surrounding circle, representing the application of the knowledge generated (Ilott et al., 2013). This implies that knowledge is always changing within the process. Within the inner triangle of the model,

“knowledge creation involves finding out what is already known about a topic, tailoring this information and producing tools to support the change in practice” (p. 2).

The action cycle is the process required to implement knowledge (Graham et al., 2006). In the past, the term knowledge transfer was considered to be a unidirectional transfer of information, but currently the term has been recognized as a two way process (Graham et al., 2006). Before healthcare providers can tailor educational programs to meet the needs of target populations, we must understand the needs of caregivers. In terms of food allergy education, multiple health care providers educate and train caregivers, yet epinephrine is still not used. Therefore, instead of healthcare providers bestowing education upon caregivers in a unidirectional manner, this study will enable caregivers to provide insight to healthcare providers particularly in regards to barriers to treatment, in attempts to develop and deliver better strategies for knowledge uptake.

Recently, more literature has been dedicated to describing the importance of understanding barriers in practice in an attempt to improve dissemination and delivery of evidence based medicine (Cochrane et al., 2007). It is known that beliefs about an individual’s capabilities are the main component to barriers and facilitators (Straus, Tetroe, & Graham, 2013). Facilitators can be defined as the circumstances, knowledge, or skill that enable an appropriate course of action to proceed as planned.

Through this project we explored the barriers and facilitators as well as uncover other factors associated with epinephrine use, or lack thereof. Cochrane (2007) states that “interventions designed to change practice must be based on an accurate assessment of the needs that support and impede targeted health outcomes” (p. 95). Using the initial parts of the K2A Cycle, this study identified the under use of EAI’s by caregivers for treatment for anaphylaxis as

a specific problem. By conducting a qualitative study, in-depth information was generated from caregivers that assessed specific barriers and facilitators with use of EAI on a child suffering anaphylaxis. Based on study findings, caregivers all expressed the importance of education soon after diagnosis. The majority of caregivers communicated a need to hear from other parents living with a child with food allergies, in addition to learning more from health care professionals. This supports the next stage of the K2A Cycle, to tailor implementation strategies. Implementation of tailored education strategies have been shown to be an effective knowledge translation technique (LaRocca, Yost, Dobbins, Ciliska, & Butt, 2012). The next step could include a video based educational tool from the perspective of a parent. Incorporating caregivers into the educational process as peer mentors and even advocates fits with the K2A cycle goals of keeping stakeholders involved in the process.

Study Strengths and Limitations

Study strengths include the study design. A phenomenological study allows for collection of rich data with detailed accounts of participants' thoughts, feelings and experiences. This study had representation of both genders. The majority of caregivers who participated in this study had food allergy education from the Children's Allergy and Asthma Education Centre in Winnipeg before they were interviewed. This can be a strength and limitation in this study. The strength would include having education and training from a health care professional on recognizing and treating an anaphylactic reaction. Having education could bias behaviour by providing a sense of security due to awareness about signs and symptoms. Also this can be a study limitation, because the perceptions and experiences could be very different in caregivers who have never participated in a food allergy program. Another limitation is that all participants are from a higher socioeconomic status (household income greater than \$75,000). These participants can

afford EAIs and are more likely to have medical insurance that covers some of the cost.

Financial considerations are an important factor that may impact the decision to use an EAI, and we acknowledge that this population demographic (low income) was not enrolled, captured, or identified. Another limitation would include that all caregivers who were interviewed were biological parents to the child with food allergies. It is possible that other caregivers, such as foster parents or relatives, may have different thoughts and experiences..

Although themes reached saturation, purposive sampling of 10 study participants can limit the transferability of the findings to the general population, and caution should be taken..

Implications for Practice, Policy and Education

There is a need for health care professionals to understand and appreciate the mental health aspects associated with food allergies in children and their caregivers. Having caregivers' emotions validated by health care professions provides ongoing support. As part of formal allergy education, there needs to be a mental health component so that caregivers understand that symptoms such as anxiety and fear are common and can be managed.

Parent advisory boards are becoming more common. Although the caregivers in this study have firsthand experiences with a child with anaphylaxis, they are all advocates for their child, and wanted to make a difference for all children with food allergies by being part of research. We need to include parents and caregivers when implementing policy and education. Their ideas and suggestions will help focus education and improve patient uptake as well as push policy forward.

Implications for Research

The next steps to this research may include creating and developing an educational video featuring caregivers telling their stories about living with a child with food allergies. This could

then be used in focus groups and further evaluated to understand how these videos impact other caregivers.

Summary

The findings of this study indicate the need for health care professionals to address, educate and prepare parents for the myriad of emotions, thoughts and behavioral responses that are encountered when parents live with children with food allergies. Health care providers must further help manage caregiver's anxieties and concerns when it comes to administering EAI for a life-threatening reaction. Fear and anxiety cause hesitation and are thus sources of subsequent guilt. When health care providers teach that these feelings are common, and reinforce the importance of prompt administration of EAI, caregivers will be reassured that these emotions and doubts are part of the normal process of treating a child. It cannot be over stated that use of an EAI cannot hurt a child and there are no contraindications to their use.

Health care providers have a responsibility to their patients to provide the best current care, and reinforce proper treatment. In a system where health care can be delivered by several different professionals, including physicians, nurses, nurse practitioners, and physician assistants to name a few, it is imperative that the same information is being disseminated and the same treatment given to all patients. Health care providers do a disservice when they learn and teach one action, but then act differently in practice. The guidelines regarding anaphylaxis are quite literally life and death. Health care providers cannot afford to be inconsistent in the delivery of care and education to patients and their families. Health care providers must understand that caregivers are dependent on health care providers to keep their child safe. All health care professionals must advocate and demonstrate prompt epinephrine administration. Listening to the experiences of parents who have witnessed their child go through life-threatening reactions

can be an invaluable source of experience and this information can be used to help educate, support, and guide other caregivers.

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APPENDICES

Appendix A - Consent Form



UNIVERSITY
OF MANITOBA

Faculty of Health Sciences

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

Title of Study: Caregivers' Perceptions and Experiences with Epinephrine Use During a Child's Anaphylactic Reaction

Principal Investigator: Rishma Chooniedass
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Sponsor:

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose of Study

In the last few decades, there has been a rise in food allergies. Caregivers manage food allergies in children. The purpose of this study is to understand caregivers' perceptions and experiences with epinephrine auto injector use during their child's anaphylactic reaction. You are being invited to take part in this research because we feel that your experience as a caregiver can contribute much to our understanding and knowledge of food allergy management.

Study Procedure

If you chose to take part in this study, you will be asked to attend the Thompson Children's Allergy & Asthma Centre at the Health Sciences Centre or a location convenient to you, once or twice to take part in a one to one interview with the researcher. You will be asked to talk about your child's food allergy and past anaphylactic reactions, outlining your experiences, thoughts and feelings. The session will take approximately 1 hour. The researcher will take notes and the interview will be audio recorded and transcribed by a study staff. You will be given contact information for the researcher in case you want to provide further thoughts following the interview. Your child's hospital chart may be accessed to confirm details of your child's last hospitalization for anaphylaxis, and you may be asked to return for a second interview.

Participant's No _____
Version 1 – April 2015

Participant's initials _____

Study Title: Caregivers' Perceptions and Experiences with Epinephrine Use During a Child's Anaphylactic Reaction

Possible Risks and Discomfort

This study is not expected to cause any increased risk or discomfort. We are asking you to share some personal information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question if you don't wish to do so, and you do not need to give a reason for not responding.

Benefits

There may not be direct benefit to you from participating in this study. We hope the information learned from this study will benefit how other caregivers manage their child's anaphylactic reaction.

Cost for participation

There will be no added cost to you for taking part in this study. Parking will be reimbursed and to thank you for your time, a \$10.00 gift card will be given to you at the end of the interview.

Confidentiality

Personal Health Information Act guidelines will be used at all times to ensure confidentiality. You will be assigned a study number and it will be used in study files rather than your name. All personal information including names and consent form will be kept secure in a locked location separate from the database for seven years. The recorded interviews will only be available to the study researchers and the study staff member transcribing the recordings. The health information collected as part of this study will be kept confidential unless release is required by law, and will be used only for the purpose of the research study.

Data will be stored in a central encrypted server and housed in Winnipeg. The database will have firewalls to secure all information, and allow access by only authorized, password-protected user accounts. This will ensure all study participant information remains confidential and safe.

Information from this study may be published or presented in public forums, however your name and other identifying information will never be used or revealed. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as:

The University of Manitoba Education/Nursing Ethics Board may review research-related records for quality assurance purposes. Voluntary Participation/Withdrawal from the Study

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate in any or all parts of the study and you may withdraw from the study at any time. Your decision not to take part or to withdraw from the study will not affect your other care at this site.

Participant's No _____

Version 1 – April 2015

Participant's initials _____

Study Title: Caregivers' Perceptions and Experiences with Epinephrine Use During a Child's Anaphylactic Reaction

Debriefing and Dissemination

The knowledge gained from this research will be shared with you before it is made public. You will receive a summary of the results by August 2015 (by mail or email). Informational pamphlets will be created to help other caregivers that are managing a child food allergy. The results will be presented at scientific conferences and published in a journal so that others learn from the research.

Questions

You are free to ask any questions that you may have about your interview and your rights as a research participant. If any questions come up during or after the study or if you have a research-related injury, contact the study staff:

The total time for this will be about 1-2 hrs.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator (HEC) at 204-474-7122. A copy of this consent form has been given to you to keep for your records and reference.

I give permission to access my **child's** hospital chart Yes No

In the future, would you be willing to participate with sharing your story publicly to assist other caregivers? Yes No

Participant's printed name: _____ Date _____

Participant's signature: _____

Researcher's printed name: _____ Date _____

Researcher's signature: _____

Participant's No _____

Participant's initials _____

Version 1 – April 2015

Appendix B - Demographics Form

Demographic Form

Do NOT put your name on this paper. You may choose not to answer any question.

Study ID: _____

Date: [___ / ___ / ___] (dd/mmm/yyyy)

1. Type of Caregiver:

- | | |
|-----------------------------------|---|
| <input type="checkbox"/> Mother | <input type="checkbox"/> Relative |
| <input type="checkbox"/> Father | (grandparent, aunt, uncle, sibling etc) |
| <input type="checkbox"/> Guardian | <input type="checkbox"/> Other Specify: _____ |

2. Gender

- Male
 Female
 Transgender

3. Date of Birth: [___ / ___ / ___] (dd/mmm/yyyy)

4. Level of school completed:

- High School
 Post-Secondary Certificate
 Post-Secondary Diploma
 Post-Secondary Degree

5. Marital Status:

- | | |
|-------------------------------------|------------------------------------|
| <input type="checkbox"/> Single | <input type="checkbox"/> Separated |
| <input type="checkbox"/> Common law | <input type="checkbox"/> Divorced |
| <input type="checkbox"/> Married | <input type="checkbox"/> Widowed |

6. Employment:

- Unemployed
 Employed
 Self-Employed

7. Annual household income:

- | | |
|--|--|
| <input type="checkbox"/> <\$5,000 | <input type="checkbox"/> \$35,000~\$50,000 |
| <input type="checkbox"/> \$5,000~\$10,000 | <input type="checkbox"/> \$50,000~\$75,000 |
| <input type="checkbox"/> \$10,000~\$15,000 | <input type="checkbox"/> \$75,000~\$100,000 |
| <input type="checkbox"/> \$15,000~\$20,000 | <input type="checkbox"/> \$100,000~\$125,000 |
| <input type="checkbox"/> \$20,000~\$25,000 | <input type="checkbox"/> \$125,000~\$150,000 |
| <input type="checkbox"/> \$25,000~\$35,000 | <input type="checkbox"/> >\$150,000 |

Child's Information:

8. Child's Allergy (Mark all that apply):

- | | |
|------------------------------------|------------------------------------|
| <input type="checkbox"/> Peanut | <input type="checkbox"/> Fish |
| <input type="checkbox"/> Tree nuts | <input type="checkbox"/> Shellfish |
| <input type="checkbox"/> Egg | <input type="checkbox"/> Sesame |
| <input type="checkbox"/> Milk | <input type="checkbox"/> Other |
| <input type="checkbox"/> Wheat | Specify: _____ |
| <input type="checkbox"/> Soy | |

9. Child's date of birth: [___ / ___ / ___] (dd/mmm/yyyy)

10. Age of Diagnosis: _____ years

11. Diagnosed by:

- | | |
|---|---|
| <input type="checkbox"/> Pediatrician | <input type="checkbox"/> Family doctor |
| <input type="checkbox"/> Allergist | <input type="checkbox"/> Emergency doctor |
| <input type="checkbox"/> Nurse Practitioner | |

12. Initial epinephrine prescriber:

- | | |
|---|---|
| <input type="checkbox"/> Pediatrician | <input type="checkbox"/> Family doctor |
| <input type="checkbox"/> Allergist | <input type="checkbox"/> Emergency Doctor |
| <input type="checkbox"/> Nurse Practitioner | |

13. Initial epinephrine trainer:

- | | |
|---|-------------------------------------|
| <input type="checkbox"/> Pediatrician | <input type="checkbox"/> Nurse |
| <input type="checkbox"/> Allergist | <input type="checkbox"/> Pharmacist |
| <input type="checkbox"/> Family doctor | <input type="checkbox"/> Other |
| <input type="checkbox"/> Emergency doctor | Specify: _____ |

14. Carries an epinephrine auto-injector:

- Yes
 No

15. Number of anaphylactic reactions: _____

16. Number of times used an epinephrine: _____

Semi-Structured Interview Guide

Introduction to the Interview: I would like to learn more about your perspectives and experiences using or not using an epi-pen when your child has anaphylaxis.

Note: Probes will only be used as necessary to elicit further discussion.

1. Can you tell me about your child's food allergy?
2. Can you tell me what does the term, anaphylaxis, mean to you?
3. Can you tell me about a specific situation when your child experienced anaphylaxis?
 - a. When thinking back to that situation, what were your thoughts? What were your feelings?
 - b. Were there other people influencing your decision or other person that you were talking to about the reaction?
4. Please share what you know about the epi-pen.
 - a. How did you learn about using an epi-pen?
 - b. How often do you review/train on auto-injector technique with a health care provider?
 - c. At what point do you use the auto-injector?
5. When [name of child] experienced anaphylaxis, please describe how you managed the situation. When you think back to that [situation], what were your thoughts and feelings about using the epi-pen at that time?
6. What are your suggestions about better ways to help people become more comfortable and more skilled at using epi-pens?
7. Is there anything else that you would like to tell me?

Hospital Chart Extraction Questions:

Confirm age, date of birth, known allergies.

- 1) Emergency Entrance Diagnosis
- 2) Triage Date and Time
- 3) Signs and Symptoms
- 4) Suspect Trigger
- 5) Emergency Treatment(s)
- 6) Pre- Emergency Medications
- 7) Discharge Diagnosis
- 8) Discharge instructions
- 9) Discharge Time