# Lived Experiences of Food-Allergic Young Adults in Differentiating Anxiety from Anaphylaxis in the Aftermath of A Severe Allergic Reaction

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#### Abstract

The physiological and psychological distress symptoms associated with anxiety are markedly similar to those seen in anaphylaxis, making it difficult to differentiate between the two acute reactions (Manassis, 2012). Research suggests that medically traumatic events like anaphylaxis have the potential to perpetuate brain-body disconnections (e.g., decreased interoceptive accuracy, increased sensitivity to interoceptive signals) that make it increasingly challenging to differentiate the overlapping symptomatology (Schaan et al., 2019; Manassis, 2012; Joshi, Aupperle, & Khalsa, 202). The misinterpretation of anxiety symptoms as medical emergencies is a well-known phenomenon in healthcare and emergency medicine, but has yet to be specifically explored in the context of food allergy. This study employed a mixed-methods research design to explore the functional impact of posttraumatic stress symptoms (PTSS) on survivors of foodinduced anaphylaxis. The study gathered allergic disease and mental health data from twenty (n=20) food-allergic young adults. 65% of participants (n=13) reported that sometimes they cannot differentiate between anxiety and anaphylaxis symptoms. Five (n=5) participants who endorsed PTSS were further interviewed. Common themes across their interviews captured a shared lived experience of anxiety while attempting to authenticate anaphylaxis symptoms. It is the hope that the results of this investigation will provide healthcare professionals with a greater understanding of the psychological impacts of anaphylaxis and contribute to the future development of evidence-based prevention strategies and/or treatment protocols to alleviate undue psychosocial burden in this community.

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## **Chapter 1: Nature of the Study**

## **Background**

This study aims to capture and describe the shared lived experiences of the food allergy (FA) community in the aftermath of a severe reaction. The purpose of this chapter is to provide a foundational basis for the research purpose and direction. The chapter is divided into seven sections, which will offer a preliminary backdrop for the research context, focus, and significance. The sections are as follows: Problem Statement, Purpose of the Study, Research Questions, Theoretical Framework, Scope of the Study, Significance of the Study, and Summary.

## **Problem Statement**

Approximately 11% of adults in the United States have a food allergy (Gupta et al., 2019), and in the absence of effective prevention strategies, food allergy prevalence continues to rise in the United States (Warren et al., 2020). Individuals with IgE-mediated food allergies have been found to have lower quality of life and higher levels of emotional distress compared to their non-food allergic peers (Polloni & Muraro, 2020; Warren et al., 2020). In a recent global study, 67.7% of adults and 77.2% of caregivers reported psychological distress related to their or their child's food allergy (Knibb et al., 2024). Yet, the majority of food allergy research efforts are directed towards diagnosis and treatment, rather than the psychological ramifications of living with the chronic condition (Feng & Kim, 2019). Beyond the considerable mental health consequences of routine day-to-day allergic disease management, the threat of an acute, life-threatening allergic reaction also looms.

Nearly 51% of adults with FAs have experienced a severe food-induced allergic reaction over the course of their lifetime (Gupta et al., 2018). Anaphylaxis is an acute, immune system response characterized by its risk for respiratory compromise and cardiovascular collapse

(AAAI, 2022). Beyond its physiological impacts, anaphylaxis is also associated with significant psychological consequences, including posttraumatic stress symptoms (PTSS), anxiety, depression, somatic problems, and social dysfunction (Chung et al., 2011; Tal et al., 2019). The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision* (DSM-5-TR) (2022) directly identifies anaphylactic shock as a life-threatening medical emergency that meets diagnostic criteria for a trauma and stressor-related disorder. The physiological and psychological symptoms associated with anxiety are markedly similar to those seen in anaphylaxis, making it difficult to differentiate between the two acute reactions. Research suggests that medically traumatic events like anaphylaxis have the potential to perpetuate brain-body dysregulations that would make it increasingly challenging to differentiate the overlapping symptomatology (Schaan et al., 2019; Manassis, 2012; Joshi, Aupperle, & Khalsa, 2023). The misinterpretation of anxiety symptoms as medical emergencies is a well-known phenomenon in healthcare and emergency medicine, but has yet to be specifically explored in the context of food allergy.

## **Purpose of the Study**

Further investigation into the psychosocial burdens of chronic allergic disease management is warranted. This study focuses on the psychological impacts of food-induced anaphylaxis. This research took a mixed-methods approach to understanding the functional impacts of PTSS on food-allergic young adults following a severe allergic reaction. The investigation intends to capture and describe the shared lived experiences of the food allergy community while attempting to effectively differentiate anxiety symptoms from anaphylaxis symptoms.

## **Research Questions**

The guiding question for the study is as follows: What is the functional impact of posttraumatic stress symptoms (PTSS) on survivors of food-induced anaphylaxis? The study is further grounded by two subquestions:

- 1. What is the experience of food-allergic young adults in distinguishing anxiety symptoms from anaphylaxis symptoms?
- 2. How do food-allergic young adults attempt to distinguish anxiety symptoms from anaphylaxis symptoms, and is it effective?

## **Theoretical Framework**

To capture and describe the shared lived experience of the FA community postanaphylaxis, a mixed-methods approach was indicated. Quantitative data collection followed an
observational research design to gather prevalence and incidence data about food allergies and
mental health from the participants. However, a purely quantitative focus would have failed to
capture the individual voices and first-person recollections of the participants in this study.

Phenomenological data collection was able to expand upon the descriptive statistics and
personify the personal experiences of the FA community. In all, the mixed-methods approach
was best suited to decipher the collective meaning of attempting to distinguish between anxiety
and anaphylaxis symptoms.

## Significance of the Study

A greater understanding of the psychological impacts of food-induced anaphylaxis has clinical relevance for both medical and mental health professionals. It is the hope that increased awareness of anaphylaxis as a medically traumatic event will guide the next generation of researchers towards developing screening measures, diagnostic tools, and treatment protocols

that can address the psychosocial needs of the FA community. Such intervention strategies will better inform the work of clinicians who care for patients with food allergies, including allergists/immunologists, primary care doctors, emergency room personnel, and mental health professionals. By amplifying FA voices and fostering stronger interdisciplinary collaboration across FA providers, we can pave the way towards relieving undue psychosocial burden in this community.

## **Chapter 2: Literature Review**

## **Allergic Disease**

The purpose of this section is to offer a broad overview of allergic disease and to provide a foundational understanding of food allergy prevalence, diagnostics, treatment, and prevention.

## **Introduction to Food Allergies**

A food allergy (FA) is a chronic and potentially life-threatening health condition mediated by allergen-specific immunoglobulin (IgE). Food allergies are a key component of what immunologists consider the Atopic March, or the "natural history of allergic disease manifestations that often progresses from allergic sensitization early in infancy to atopic dermatitis, food allergy, asthma, and allergic rhinitis" (Warren et al., 2020, p. 1). Food allergies are estimated to affect 1 in 10 (11%) adults and 1 in 12 (8%) children in the United States (Warren, Jiang, & Gupta, 2020). Food allergies can develop at any time across the lifespan, not just during childhood. It is estimated that 5.2% of adults, or nearly 12 million Americans, are living with an adult-onset food allergy (Gupta et al., 2019). Approximately 90% of all FAs can be accounted for by nine foods: Peanut, tree nut, wheat, milk, soy, egg, shellfish, finfish, and sesame (American Academy of Allergy, Asthma, and Immunology, 2022). Contact with or the ingestion of a food allergen can result in an allergic reaction. An IgE-mediated allergic reaction can produce symptoms ranging from mildly uncomfortable (e.g., itching) to severe and life-threatening (e.g., anaphylaxis).

## **Etiology**

Food allergies develop through sensitization (NIAID, 2023). Sensitization is the creation of immunoglobulin (IgE) antibodies in response to exposure to an allergen protein (NIAID, 2023). The allergen-specific IgE antibodies live in the bloodstream of the immune system

(NIAID, 2023). When the body is subsequently exposed to the allergenic protein, the protein binds to the IgE antibodies attached to the immune cells (NIAID, 2023). This binding prompts the immune system to release certain chemicals, initiating the allergic response (NIAID, 2023). While the biology of this reactivity process is largely understood, allergists and immunologists (A/Is) still have many unanswered questions about the basic etiology of FA (NIAID, 2023). According to the National Institute of Allergy and Infectious Diseases (2023), scientists are unsure why some individuals develop these allergen-specific IgE antibodies, while others do not. The theories that have been posed appear to have elements of both nature and nurture (NIAID, 2023).

Several risk factors have been identified. The leading risk factor for developing FA is a history of atopic dermatitis (NIAID, 2023). Atopic dermatitis, commonly referred to as eczema, is an inflammatory skin condition mostly seen in children and adolescents (NIAID, 2023). Children with moderate to severe eczema are more likely to develop FAs than those with mild or no history of eczema (NIAID, 2023). FAs also appear to have a significant genetic component and high heritability rates (NIAID, 2023).

According to the National Center for Health Statistics, there was a 50% increase in the prevalence of FA among children between 1997 and 2011 in the United States (Jackson, Howie, Akinbami, 2013). While researchers offer some insight into the risk factors for developing FA, there is no consensus as to why FA incidence is increasing. One theory is that environmental factors are adversely affecting the functioning of the human immune system (NIAID, 2023). It is hypothesized that an increase in the use of antibiotics and hand sanitizers, hygienic living environments, and cesarean section births may be weakening gut microbiomes (NIAID, 2023).

## **Anaphylaxis**

Anaphylaxis is an acute immunological systemic reaction most commonly seen in response to food, insect bites, venom, medications, or latex (AAAAI, 2022). Characterized by its risk for respiratory compromise and cardiovascular collapse, anaphylactic shock can be fatal (AAAAI, 2022). Anaphylaxis can be recognized by the presence of an immune system response in at least two bodily systems – Gastrointestinal, dermal, respiratory, and/or cardiovascular (AAAAI, 2022). Anaphylaxis symptoms can include the swelling of bronchial tissues, shortness of breath, difficulty swallowing, chest tightness, stomach cramping, vomiting, diarrhea, sudden drop in blood pressure, and/or loss of consciousness (AAAAI, 2022). According to the American Academy of Allergy, Asthma, and Immunology (2022), the treatment of anaphylactic shock requires immediate medical attention, including the administration of an epinephrine autoinjector (EAI) followed by an emergency department evaluation.

Food-induced anaphylaxis is relatively common. Approximately 40% of food allergic children and 51% of food-allergic adults have experienced a severe allergic reaction, with nearly a third of food allergic individuals seeking emergency room services for a food-induced anaphylactic reaction over the course of their lifetime (Gupta et al., 2018; Gupta et al., 2019). In contrast, fatal food-induced anaphylaxis is relatively rare, with an estimated range of 0.03 to 0.30 deaths per one million persons (Turner et al., 2017). The underlying mechanisms are complex, and experts are not able to reliably identify patients most at risk of fatal food-induced anaphylaxis (Turner et al., 2017). Epidemiologists have found that peanut allergies are the leading cause of fatal food-induced anaphylaxis (Togias et al., 2016). While anaphylaxis is most commonly reported in children, fatal food-induced anaphylaxis is most common among adolescents and young adults (Turner et al., 2017). Further, while the delayed administration of epinephrine and upright bodily positioning during a reaction are both associated with fatal

outcomes, experts admit that there is limited research into how to reduce risk for anaphylactic lethality (Turner et al., 2017).

The underlying mechanisms behind allergic reactions are complex and remain incompletely understood. The severity and dosage threshold of anaphylactic reactions can be influenced by augmenting factors called cofactors. Some cofactors include exercise, alcohol, sleep deprivation, anti-inflammatory drugs, estrogen levels, and even emotional distress (Muñoz-Cano et al., 2017). In the presence of one or more of these cofactors, the severity of an allergic reaction may increase, and the amount of allergen required to induce a reaction may decrease (Muñoz-Cano et al., 2017). Cofactors are thought to play a role in approximately 30% of adult allergic reactions (Muñoz-Cano et al., 2017).

## **Diagnosis**

According to the National Institute of Allergy and Infectious Diseases, a double-blind, placebo-controlled, oral food challenge (OFC) is the gold standard of FA diagnostics (Boyce et al., 2010). An OFC is a highly accurate immunological procedure that can be used to confirm an initial FA diagnosis, or to disconfirm a previous FA diagnosis. The standardized OFC entails feeding the patient measured doses of a potential food allergen, then monitoring for allergic reaction symptoms. Dosing gradually increases over several hours under the direct supervision of a medical professional. Vital signs are periodically monitored by immunology specialists for several hours following ingestion. If the patient shows any warning signs of an allergic reaction, the OFC is discontinued and appropriately treated. However, if the patient completes the OFC without significant symptomatology, the FA can be effectively ruled out (Boyce et al., 2010). OFCs are routinely conducted in outpatient allergy and immunology clinics and considered to have an excellent safety record (Boyce et al., 2010). However, OFCs are time-consuming,

expensive, and put the food-allergic person at increased risk for a severe reaction (Boyce et al., 2010). Despite the accuracy of OFCs, these inherent drawbacks lead other diagnostic tools to be more commonly utilized in everyday practice.

Allergists and immunologists routinely diagnose FAs with a combination of blood serum and skin prick tests by measuring the presence of IgE antibodies in the bloodstream (Boyce et al., 2010). Compared to OFCs, blood and skin prick tests are more time and cost-efficient, and have a limited risk for severe reactions. However, allergen-specific IgE testing is less precise. IgE testing alone is not diagnostic by nature because it reflects allergic sensitization rather than clinical FA. Consequently, blood serum and skin prick tests have low positive predictive power for making an initial diagnosis of FA (Boyce et al., 2010). This type of testing is also known for its high sensitivity and low specificity, which increases the risk for an improper FA diagnosis (Boyce et al., 2010). This may lead to a cascade of behavioral, socioemotional, and financial consequences, including unnecessary food avoidance and needless medication prescriptions. Given these complexities of FA diagnostics, a thorough review of medical history is recommended to corroborate a FA diagnosis (Boyce et al., 2010).

## **Treatment**

According to the American Academy of Allergy, Asthma, & Immunology (2023), there is no cure for FAs. The National Institute of Allergy and Infectious Diseases' (NIAID)

Guidelines for the Diagnosis and Management of Food Allergy in the United States instead focuses on the prevention of allergic reactions (Boyce et al., 2010). The leading recommendation for the prevention of food-induced allergic reactions is strict avoidance (AAAAI, 2023). The NIAID guidelines identify "dietary avoidance of specific allergens" as the standard treatment protocol for the overall management of FA (Boyce et al., 2010). Other recommendations include

nutrition counseling, regular growth monitoring of children, education in food label interpretation, and routine A/I specialist check-ups (Boyce et al., 2010). In the event of a severe allergic reaction, patients are instructed to follow their 'Anaphylaxis Action Plan' by administering EAI and seeking immediate medical attention (AAAAI, 2023).

Since the year that the National Institute of Allergy and Infectious Diseases (NIAID) first developed its clinical guidelines for the diagnosis and treatment of FAs in 2008, continued research in the field of allergy and immunology has allowed for an expansion of the recommendations (Togias et al., 2016). In addition to strict avoidance, certain therapeutic interventions are now being recommended and offered by A/I specialists. For example, oral immunotherapy (OIT) is an investigational treatment protocol that uses systematic desensitization to treat single FAs (AAAAI, 2020). Although not curative, OIT can help protect against accidental exposures by raising the threshold of protein necessary to induce an allergic reaction (AAAAI, 2020). Palforzia<sup>TM</sup>, indicated for patients ages 4 to 17 with an IgE-mediated peanut allergy, is the only FDA-approved OIT treatment in the United States (AAAAI, 2020). Clinical trials have also demonstrated the effectiveness of this protocol for egg and milk allergies, with desensitization rates ranging from 60% to 80% (AAAAI, 2020). While early studies produced promising results, such immunotherapies are expensive and time consuming, making them largely unavailable to the vast majority of the FA community.

## **Prevention**

In the absence of effective and reliable therapies for the treatment of FAs, researchers have focused attention on methods for preventing the onset of FAs altogether. The Learning Early about Peanut Allergy (LEAP) trial was the first to study early allergen introduction as a method of FA prevention (Togias et al., 2016). In 2015, LEAP published its findings on the

effectiveness of early allergen introduction as a method of FA prevention. The randomized control trial demonstrated a 70% to 86.1% relative reduction in the development of peanut allergy using early introduction (Togias et al., 2016). This approach is in direct contradiction to previously established medical advice to avoid allergen exposure in early childhood.

Consequently, the implementation of this prevention strategy has been slow to be adopted among caregivers.

## **Demographics**

## Age

The prevalence of food allergies differs across age groups. Approximately 8% of US children have a FA (Warren, Jiang, & Gupta, 2020). The most commonly reported FAs among children are peanut (2.2%), milk (1.9%), shellfish (1.3%), tree nut (1.2%), and egg (0.9%) (Gupta et al., 2018). Incidence rates in children are estimated to peak around age two (10%) (Sicherer et al., 2020). Of the 5.6 million children with a FA, 42.3% have experienced a severe food-induced allergic reaction (Gupta et al., 2018). Milk, egg, wheat, and soy allergies are more likely to resolve in childhood, whereas peanut, tree nuts, fin fish, and shellfish tend to persist into adulthood (Sicherer et al., 2020).

Approximately 11% of US adults have a food allergy (Warren, Jiang, & Gupta, 2020). The incidence of FA is higher in adult populations than in pediatric populations. Adult FAs may be in continuation from childhood-onset FAs, or be adult-onset FAs. Forty-eight percent of food-allergic adults report that they developed a FA in adulthood (Gupta et al., 2019). In all, it is estimated that 5.2% of US adults, or nearly 12 million Americans, are living with an adult-onset FA (Gupta et al., 2019). The most commonly reported FAs among adults include shellfish (2.9%), peanut (1.8%), milk (1.9%), tree nut (1.2%), and fin fish (0.9%) (Gupta et al., 2019).

While seafood and tree nuts appear to be the most frequently diagnosed adult-onset FAs, research suggests that adult-onset FAs can be developed for any allergen group (Gupta et al., 2019). Of the more than 26 million US adults with a FA, an estimated 51.1% have experienced a severe allergic reaction, and 38.3% have sought FA-related emergency room services in their lifetimes (Gupta et al., 2019).

## Sex

The prevalence of FA differs across sexes. The role of sex in FA appears to be moderated by age (Pali-Scholl & Jensen-Jarolim, 2019). In children under the age of six, rates of FA are higher in males; Yet among adults, rates of FA are higher in females (Pali-Scholl & Jensen-Jarolim, 2019). This disparity in FA diminishes around menopause, suggesting an impact of hormones and metabolism on FA expression (Pali-Scholl & Jensen-Jarolim, 2019).

## Race/Ethnicity

Atopic conditions are unequally distributed across racial and ethnic groups (Jiang et al., 2023). Food allergies disproportionately impact non-White communities in the United States (Jiang et al., 2023). Epidemiological findings suggest that FA rates are higher in Black (10.6%), Hispanic (10.6%), and Asian (10.5%) populations, compared to non-Hispanic White cohorts, even when controlled for household income, educational level, and other covariates (Jiang et al., 2023; Gupta et al., 2019). The burden of FA is also greater in these communities, as Black and Hispanic individuals report more severe allergic reactions and more allergy-related emergency room visits than their White counterparts (Jiang et al., 2023; Gupta et al., 2019). The following discussion on social determinants of health will offer greater insight into why this may be the case.

## **Social Determinants of Health**

Social Determinants of Health (SDOH) are the social and environmental factors that impact health, well-being, and quality of life, including economics, education, healthcare, neighborhood, and community (Healthy People 2030). SDOH are known to perpetuate health inequities due to longstanding histories of racism and discrimination (Healthy People 2030). The systemic factors that put low-income communities and persons of color at increased risk of poor health outcomes are evident in FA (Cook, Argenio, & Lovinsky-Desir, 2021).

## Socioeconomic Status

There is a significant economic burden of FA. A systematic review of eleven cost-of-illness studies quantified the direct, out-of-pocket, and opportunity costs of FA management. According to their estimates, average individual-level direct costs (e.g., medications, lab work, hospitalizations) totaled \$2,081, and the average household-level out-of-pocket costs (e.g., allergen-free foods, safe childcare) totaled \$3,839 (Bilaver et al., 2019). The greatest economic burden was imposed by household-level opportunity costs (e.g., decreased labor productivity, loss of leisure activity, increased time spent on FA-related information seeking), which totaled \$4881 (Bilaver et al., 2019).

The significant economic burden of FA has been a topic of state and federal legislation. Epinephrine auto-injectors (EAI) are the only Food and Drug Administration (FDA) approved devices for the emergency treatment of anaphylaxis (Jiang et al., 2023); however, rising prices have made the life-saving medication inaccessible for many households (Mondello, 2023). In 2016, the cost of a two-pack prescription of Epi-Pen™ brand EAIs rose 500% to approximately \$600 (Mondello, 2023). This helps explain, in part, why only 24% of food-allergic adults and 40.7% of food-allergic children in the United States have a current prescription for an EAI (Gupta et al., 2018; Gupta et al., 2019). Recent legislative efforts have since worked to cap the

price of EAIs at \$60, with success in eight states across the United States (Mondello, 2023). The Epinephrine's Pharma Inflated Price Ends Now (EPIPEN) Act was introduced to the U.S. House of Representatives in 2024 with the hopes of enacting change on the federal level.

The financial strain of FA is disproportionately felt by low SES families. FA is disproportionately prevalent in low-income families in the United States (Jiang et al., 2023). Historically, health care inequities have limited community access to FA diagnostic testing offered by A/I specialists, and in turn, the prevalence of FA in low-income communities has traditionally been underestimated. However, new epidemiological research has instead found that FA rates are lowest among individuals with household incomes greater than \$150,000 annually (Jiang et al., 2023). While individuals of lower socioeconomic status (SES) are more likely to have FAs, compounding costs make it less likely that they can effectively manage their dietary restrictions.

Socioeconomic disparities and healthcare inequalities put low-income families at an overall disproportionate risk for negative FA outcomes (Jiang et al., 2023). For example, rates of anaphylactic allergic reactions are higher among low-income families (Jiang et al., 2023). The increased prevalence of allergic reactions is associated with poorer access to routine A/I care, compared to high SES households (Jiang et al., 2023). For example, most private A/I practices do not accept Medicaid coverage (Jiang et al., 2023). Academic medical centers that accept Medicaid are concentrated in urban areas, limiting accessibility to rural and suburban families (Jiang et al., 2023). Without access to specialty care, low-income families are less likely to be properly diagnosed with a FA and less likely to be educated on how to prevent and treat the chronic condition (Jiang et al., 2023).

Higher rates of anaphylactic allergic reactions among low-income families are also

related to poorer access to foods that do not contain their allergens. Specialty food products dedicated to being free from common allergens are both expensive and difficult to obtain, making their acquisition particularly challenging for low-income households. Research suggests that families utilizing government-sponsored nutrition programs have significant difficulty obtaining safe foods (Jiang et al., 2023). In a 2022 study, less than half (46.4%) of families using government-sponsored nutrition programs were always able to find allergen-free food options (Frame et al., 2022).

## Health Literacy

The World Health Organization (WHO) defines health literacy as:

representing the personal knowledge and competencies that accumulate through daily activities, social interactions, and across generations. Personal knowledge and competencies are mediated by the organizational structures and availability of resources that enable people to access, understand, appraise, and use information and services in ways that promote and maintain good health and well-being for themselves and those around them.

In the United States, health literacy is a stronger predictor of an individual's health status than income, employment status, education level, and racial or ethnic group (WHO, 2024).

Given the complexity of allergic disease management, FA requires a certain degree of health literacy, known as food allergy literacy (FAL). FAL encompasses the knowledge of FA diagnosis, management, emergency treatment, and prevention. Yet, epidemiological research suggests food allergy literacy is relatively low. This is due, in part, to the shortage of A/I specialists available to meet the needs of the growing FA population (Marshall, 2007). Without access to these specialty care providers, families are less likely to be properly diagnosed with,

treated for, and educated about FAs (Jiang et al., 2023). Gupta (2019) suggests that greater patient education efforts need to be made in the areas of distinguishing FA from food intolerances, increasing epinephrine prescriptions and medication adherence, and promoting early allergen exposure in infancy.

## **Environmental Pollution**

The relationship between environmental exposure and abnormal lung functioning has been well-documented in asthma literature (Grant, Croce, & Matsui, 2022). Air and environmental pollution have also been found to be associated with immune system dysfunction and allergic disease sensitization (Cook, Argenio, & Lovinsky-Desir, 2021). A proposed explanation for the particular increase in shellfish allergies is related to environmental exposures (McGowan et al., 2019). Low income and poor quality housing are associated with high levels of indoor aeroallergens, such as mold, dust mites, and cockroaches (Cook, Argenio, & Lovinsky-Desir, 2021). Tropomyosin, a muscle protein found in arthropods like dust mites and cockroaches, is also the main allergen found in shrimp (McGowan et al., 2019). Research suggests that chronic exposure to these indoor aeroallergens may lead to cross-sensitization with shellfish (McGowan et al., 2019). This hypothesis may help explain why the most common allergy among adults in the United States is shellfish, with more than 7.2 million diagnoses (Gupta et al., 2019). In all, it is clear that SDOH, including socioeconomic status, food insecurity, environmental exposures, and living conditions, have a direct impact on the health of the FA community (WHO, 2023).

## **Human Stress Responses**

The purpose of this section is to describe the range of human stress responses, differentiate normative stress from clinical stress, and highlight relevant symptomatology seen in

several stress-related disorders. This section will also provide a broad overview of Polyvagal Theory as it relates to fear learning: the hypothesized mechanism that perpetuates somatic trauma responses post-anaphylaxis. The following definitions will be essential for understanding the impacts that FA can have on mental health, and the effects that trauma can have on the human stress response.

## **Defining Stress and Anxiety**

Stress is defined as the "Physiological and psychological response to internal and external stressors" (APA, 2018). Stress is a normative process that affects nearly every system within the human body (APA, 2018). Fear is distinguished from stress and defined as a "Basic, intense emotion aroused by the detection of imminent threat involving an immediate alarm reaction that mobilizes the organism by triggering a set of physiological changes" (APA, 2018). Fear serves the biological and evolutionary purpose of increasing autonomic arousal to protect us from *active* harm (APA, 2022). In contrast, worry is a temporary emotional reaction in response to *future* threats (APA, 2022). Worry is defined as a "State of mental distress or agitation due to concern about an impending or anticipated event, threat, or danger" (APA, 2018). Baseline levels of fear and worry are adaptive and serve as short-term solutions for preventing or escaping harm. However, chronic states of distress are not sustainable and may be indicative of pathology.

Despite the meaningful differences between the terms, stress, worry, and fear are often used interchangeably with anxiety. According to the American Psychological Association (APA), anxiety is instead defined by "Excessive worries that do not go away, even when there is no clear source for the anxiety or after the source of the anxiety is eliminated" (APA, 2013). While fear is a short-term, present-focused response to a specific threat, anxiety is characterized as a long-term, future-focused response to a diffuse threat (APA, 2018). Anxiety is a state of

persistent, excessive worry that is closely associated with muscle tension, vigilance, and avoidant behaviors (APA, 2013). Anxiety can be developmentally normative, subclinical, or rise to the level of a clinical disorder. Anxiety disorders, as described by the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5), are characterized by excessive fear and anxiety for at least six months (APA, 2013). Those with clinical anxiety tend to overestimate danger and exhibit levels of fear that are out of proportion to the perceived threat (APA, 2013). Chronic fear and anxiety perpetuate dysregulation of the human stress response. For the purposes of this literature review, the term anxiety will be used to describe subclinical, excessive worry.

## **Panic Attacks**

## Diagnostic Criteria

According to the DSM-5-TR (2022), a panic attack is "An abrupt surge of intense fear or intense discomfort that reaches a peak within minutes" (APA, 2022, p.235-236). At least four of the following symptoms must be present to meet diagnostic criteria for a panic attack – Accelerated heart rate, sweating, trembling or shaking, sensations of shortness of breath or smothering, feelings of choking, chest pain or discomfort, nausea or abdominal distress, feeling light-headed or faint, chills or heat sensations, paresthesia, derealization, fear of losing control, and fear of dying (APA, 2022). Panic attacks are often comorbid with other mental disorders or medical conditions (APA, 2022). They can be either expected or unexpected, depending on whether there is an obvious cue or trigger for the abrupt sense of fear (APA, 2022). Panic differs from anxiety. A panic attack is "Distinguished from ongoing anxiety by its time to peak intensity, which occurs within minutes; its discrete nature; and its typical greater severity" (APA, 2013, p. 215). Recurrent panic attacks are required for the diagnosis of Panic Disorder, as characterized by the DSM-5-TR (APA, 2022).

## **Prevalence**

The 12-month prevalence of panic attacks is estimated to be 11.2% for U.S. adults (APA, 2013). Panic attacks are more common among females than males (APA, 2013).

## Risk Factors

Risk factors for panic attacks include neuroticism and anxiety sensitivity. Stress related to physical health may also be predictive of panic attacks (APA, 2013). Panic attacks are often comorbid with anxiety, depression, bipolar, and substance use disorders (APA, 2013). Panic attacks are also a common symptom of Acute Stress Disorder and Posttraumatic Stress Disorder (APA, 2022).

## **Posttraumatic Stress Disorder**

## Diagnostic Criteria

Posttraumatic Stress Disorder (PTSD) is a psychiatric disorder developed following a traumatic event. A traumatic event, according to Criterion A of the DSM-5-TR (2022), is considered "Exposure to actual or threatened death, serious injury, or sexual violence" (p. 302). The trauma can be experienced through direct contact, third-party witnessing, or indirect exposure to aversive details of the traumatic event (e.g., first responders) (APA, 2022). Following the traumatic event, a PTSD diagnosis requires the presence of one or more symptoms from each of the following categories – Intrusive symptoms (Criterion B), avoidance (Criterion C), negative alterations in mood or cognition (Criterion D), and marked alterations in arousal or reactivity (Criterion E) (APA, 2022). The symptoms must persist for at least one month and cause significant distress or impairment to everyday functioning (APA, 2022).

## **Prevalence**

The national lifetime prevalence of PTSD among U.S. adults is estimated at 6.8%, with the highest rates among survivors of rape, military conflict, and genocide (APA, 2022). PTSD is more common among women, with prevalence rates ranging from 8.0% to 11.0% (APA, 2022). Among men, prevalence rates range from 4.1% to 5.4% (APA, 2022). It is hypothesized that such differences may be a result of the likelihood of exposure to trauma, gender differences in emotional processing, and reproductive hormones (APA, 2022).

## Risk Factors

Pretraumatic risk factors include childhood emotional problems, previous mental health disorders, and negative affectivity/neuroticism (APA, 2022). PTSD is moderately heritable (APA, 2022). Environmental factors, including lower socioeconomic status, lower intelligence, childhood adversity, and racial discrimination, increase the risk for developing PTSD (APA, 2022). Social support before and after the traumatic event serves as a protective factor against the development of PTSD (APA, 2022). PTSD is associated with reduced quality of life, lower income/education, poor social relationships, and physical health problems (APA, 2022).

## **Acute Stress Disorder**

## Diagnostic Criteria

Acute Stress Disorder follows similar patterns. The psychiatric diagnosis again requires direct contact, third-party witnessing, or indirect exposure to aversive details of a traumatic event, but is less stringent about how the event is re-experienced. Rather, Acute Stress Disorder requires a combination of nine (or more) symptoms from any of the five categories of symptomatology. The symptoms must persist for at least three consecutive days and cause significant distress or impairment to everyday functioning (APA, 2022). If symptoms persist beyond one month, the individual should be evaluated for a diagnosis of PTSD (APA, 2022).

#### Prevalence

The prevalence of Acute Stress Disorder is highest following traumas of interpersonal violence, including physical or sexual assault (19-50%) (APA, 2022). Rates are lower following non-interpersonal traumas, such as motor vehicle collisions or accidental injuries (20%) (APA, 2022). Approximately half of those diagnosed with PTSD previously met criteria for Acute Stress Disorder (APA, 2022).

#### Risk Factors

Peritraumatic risk factors include previous mental health disorders and negative affectivity/neuroticism (APA, 2022). The tendency to "Make catastrophic appraisals of the traumatic experience, often characterized by exaggerated appraisals of future harm, guilt, or hopelessness" is strongly predictive of the development of Acute Stress Disorder (APA, 2022, p. 318).

## **Partial Posttraumatic Stress Disorder**

## Diagnostic Criteria

Partial Posttraumatic Stress Disorder, or subthreshold PTSD, is considered a trauma and stressor-related disorder that does not meet full criteria for a diagnosis of PTSD. The National Vietnam Veterans Readjustment Study (1988) was the first major research study to report on the prevalence of subthreshold PTSD. Although the diagnostic criteria for subthreshold PTSD are not solidified, it is generally understood as a Criterion A trauma exposure with some combination of re-experiencing, avoidance, and hyperarousal symptoms. The DSM-5 does not have a formal diagnostic code for subthreshold PTSD, but indicates that it can be diagnosed as Other Specified Trauma and Stressor Related Disorder.

#### Prevalence

Without standardized diagnostic criteria, results of epidemiological studies estimating the prevalence of partial PTSD have varied greatly. Despite the inconclusive results, the research has consistently shown that the prevalence of partial PTSD appears to be higher than that of full PTSD. According to the National Center for PTSD (2014), the best estimate of lifetime prevalence of partial PTSD for U.S. adults is estimated to range from 6.6% to 9.8%.

## Risk Factors

Risk factors for the development of partial PTSD include demographic characteristics, trauma history, psychiatric history, exposure, and the recovery environment (National Center for PTSD, 2014). Partial PTSD is associated with significant psychiatric and medical comorbidities (National Center for PTSD, 2014).

## **Polyvagal Theory**

Polyvagal Theory, as proposed by Dr. Stephen Porges (1995), is an evolutionary understanding of the human stress response as a mechanism of the vagus nerve. It offers an explanation for the role of the autonomic nervous system (ANS) in our thoughts, emotions, behaviors, and physiological arousal. The ANS contains the Sympathetic Nervous System (SNS) and the Parasympathetic Nervous System (PSN). It is widely accepted that the SNS is responsible for initiating the fight or flight response, while the PNS is associated with its counterpart, rest and digest (Porges, 1995). More specific to Polyvagal Theory, the PSN is further divided into the Ventral Vagal Complex (VVC) and the Dorsal Vagal Complex (DVC), which comprise the vagus nerve (Porges, 1995). Polyvagal Theory is a proposed framework for describing how prolonged threat activation contributes to both psychosocial and gastrointestinal dysfunction (Kolacz, Kovacic, & Porges, 2019).

## **Arousal States**

According to the Polyvagal Theory, there are three arousal states – Social Engagement (Homeostasis), Mobilization (Fight or Flight), and Immobilization (Freeze) (Porges, 1995, 2007, 2022). The VVC of the PNS is activated during Social Engagement. This homeostatic state facilitates interpersonal connection, the immune response, intestinal motility, and mindfulness. The sense of safety that accompanies Social Engagement allows the individual to feel present, joyful, and open to new experiences. The SNS is activated during Mobilization (Porges, 1995, 2007, 2022). This threat-response state is characterized by an increase in blood pressure, heart rate, adrenaline, and pupil size. Fuel storage, digestion, and insulin activity decrease, and the body is physiologically mobilized to move towards (fight) or move away (flight) from the threat. The DVC of the PNS is activated during Immobilization (Porges, 1995, 2007, 2022). This threatresponse state represents a bodily collapse characterized by decreases in heart rate, blood pressure, muscle tone, and temperature. Rapid drops in heart rate and blood pressure may result in a temporary loss of consciousness, also known as vasovagal syncope. Fuel storage, insulin activity, and endorphins increase to support pain management. This level of arousal represents the physiological preparation for death (Porges 1995, 2007, 2022).

## Neuroception

Neuroception is the body's ability to subconsciously scan for cues of safety, danger, and threat in the external environment (Porges, 2004). The recognition and perception of external cues through neuroception influences our bodily arousal states without conscious awareness (Porges, 2004). Safety cues promote a state of Social Engagement (Homeostasis). Danger cues, whether real or perceived, induce threat-response states – Mobilization (Fight or Flight) or Immobilization (Freeze). Mobilization is biologically adaptive for managing external threats, as it is characterized by a sense of autonomy in being able to defend oneself. Immobilization has

historically been adaptive in emergencies where the individual feels helpless (Porges, 2004).

## Interoception

Interoception is the awareness of the body's internal state (Porges, 2004). It includes the recognition and perception of physiological sensations and bodily signals, such as the detection of temperature, hunger, and heart rate. Interoception plays a significant role in our regulation of emotions, decision making, and physical wellbeing. In contrast to neuroception, interoception occurs within our conscious awareness and is focused on the internal environment. To maintain homeostasis, the brain is tasked with interpreting the interoceptive signals relayed through neural pathways. Our interpretation of these interoceptive signals is not always correct. Interoceptive accuracy refers to the precision of a person's interpretation of their body's internal state (Porges, 2004). Interoception requires a degree of self-awareness and insight into the mind-body connection (Porges, 2004).

## **Application to Trauma**

Traumatic stress can alter the human stress response and lead to poor regulation of these arousal states (Schaan et al., 2019). For example, a history of traumatic stress can cause Mobilization and/or Immobilization states to be maintained even after the real or perceived threat has passed (Kolacz, Kovacic, & Porges, 2019). The threat-response states are perpetuated by disruptions to the mind-body feedback loops. Examples include increased sensitivity to danger cues, increased sensitivity to homeostatic changes in the body, and decreased interoceptive accuracy (Kolacz, Kovacic, & Porges, 2019; Schaan et al., 2019). Polyvagal Theory offers a physiological framework for understanding how the ANS influences fear learning.

## **Fear Learning**

A literature review from Joshi, Aupperle, and Khalsa (2023) further investigated the

connection between trauma, interoceptive accuracy, and threat detection through a classical conditioning lens, known as fear learning. Fear learning is the process in which a neutral stimulus is associated with an aversive outcome, leading to feelings of fear in response to a previously neutral cue (Joshi, Aupperle, & Khalsa, 2023). Joshi, Aupperle, and Khalsa (2023) hypothesized that homeostatic changes in the body can become conditioned stimuli that "trigger avoidance and higher-order conditioning of other stimuli associated with these interoceptive signals" in PTSD (Joshi, Aupperle, & Khalsa, 2023). This form of classical conditioning can "Modify how the trauma is remembered and lead to new forms of fear learning, where subtle changes in the body [such as slight increases in heart rate while at the gym] can elicit full-blown fear responses" (Joshi, Aupperle, & Khalsa, 2023). Even small changes to the body's internal homeostasis, which were previously considered to be neutral cues, become associated with the traumatic event and are catalysts for a fear response (Joshi, Aupperle, & Khalsa, 2023). Repeated exposure to reminders of the traumatic event (e.g., autonomic arousal) strengthens the conditioned fear response. This is the conceptual basis for the hypothesized mechanism that perpetuates somatic trauma responses in the aftermath of a severe allergic reaction.

# **Psychology of Allergic Disease**

The section is intended to offer a broad overview of the psychological and socioemotional impacts associated with allergic disease management.

### **Psychosocial Impact of Food Allergies**

Atopic conditions have clear physical health consequences for the affected individual. Because attention is primarily focused on the treatment and diagnosis of allergic diseases, there is less consideration given to the psychological ramifications of living with these chronic conditions (Feng & Kim, 2019). FA management is associated with anxiety, depression, and

psychological distress (Chen et al., 2020; Polloni & Muraro, 2020). In a recent global study, 67.7% of adults and 77.2% of caregivers reported psychological distress related to their or their child's food allergy (Knibb et al., 2024). Allergic diseases have a systemic impact. While FA management is centered around making daily safe food choices, careful consideration of travel, education, finances, and medical interventions is also essential, as food is heavily tied to celebration and community in many cultures. Given these intersections, the psychosocial burdens associated with atopic conditions can result in reduced quality of life, increased distress, psychiatric vulnerabilities, and disengagement from cultural practices for patients and their caregivers (Michaud & Hubbard, 2023; Cummings et al., 2010). Common psychosocial burdens include over-avoidance and hypervigilance, bullying, disordered eating behaviors, and body image disturbance.

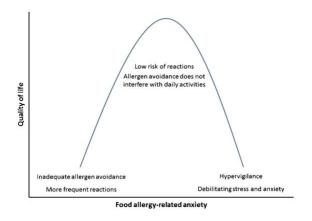
#### Avoidance

The leading National Institute of Allergy and Infectious Disease (NIAID) recommendation for the management of FA is strict avoidance (Boyce et al., 2010). While some degree of avoidance is necessary and can positively protect against allergen exposure, "The use of avoidance coping can also be problematic to psychological health" (Weiss & Marsac, 2016). FA over-avoidance is characterized by counterproductive coping strategies that go beyond what is considered medically necessary by A/I specialists. This can include restrictive dining habits, nonparticipation in otherwise desired activities (e.g., travel, sporting events), and excessive sanitation. FA over-avoidance and hypervigilance have been linked to significant mental health consequences (Feng & Kim, 2019; Polloni & Muraro, 2020). Over-avoidance can strengthen the fallacy that such prohibitive allergy precautions are necessary for survival. It has been found that these negatively biased cognitive patterns (e.g., high perceived risk, fear of death, loss of control)

can undermine the allergic patient's confidence in independently managing a threatening situation (Polloni & Muraro, 2020). The relationship between FA avoidance, FA anxiety, and quality of life is represented on a U-shaped curve defined by "The Goldilocks Principle" (Warren et al., 2016). Figure 1 suggests that there is an optimal level of FA anxiety that promotes effective disease management without fostering maladaptive hypervigilance (Warren et al., 2016). Therapeutic intervention for FA over-avoidance aims to find the delicate balance of anxiety that prioritizes safety while optimizing quality of life.

Figure 1

Hypothesized Relationship Between Food Allergy Related Quality of Life and Anxiety According to "The Goldilocks Principle"



Note. From (Warren et al., 2016).

# Food Allergy Bullying

Food allergy bullying is a form of peer victimization that targets an individual because of their FA diagnosis. Compared to the general population, the rates of bullying, teasing, and social exclusion are higher among adolescents managing chronic health conditions, such as FA (Fong et al., 2017). Children and adolescents with FA reported being bullied 1.5 times more than their non-FA peers (Fong et al., 2018). In a 2022 study of FA youth, researchers assessed the

frequency and characterization of FA bullying using the EMPOWER Program Survey of Children with Food Allergy (Cooke, Ramos, & Herbert, 2022). Nearly 31% (n=37) of the sample endorsed at least one FA victimization in their lifetime (Cooke, Ramos, & Herbert, 2022). The reported FA victimizations were physical, verbal, and relational in nature. The most frequently endorsed FA victimization was verbal teasing (51%, n = 21), followed by the overtly physical act of having an allergen waved in their face (32%, n=13) (Cooke, Ramos, & Herbert, 2022). Other overtly physical acts included having an allergen thrown at them (10%, n=4), intentionally placed in their food (5%, n=2), or being forced to eat the allergen (10%, n=4) (Cooke, Ramos, & Herbert, 2022). Physical victimizations involving intentional allergen exposure pose great safety risks. In fact, one participant in the 2022 study had suffered an allergic reaction due to FA bullying (Cooke, Ramos, & Herbert, 2022). In addition to physical consequences, FA bullying has also been found to have a profound impact on the psychosocial functioning of FA youth and their caregivers (Cooke, Ramos, & Herbert, 2022). Given the prevalence and significant risks associated with FA bullying, experts have called for the routine assessment of overt and covert FA bullying behaviors among youth cohorts (Cooke, Ramos, & Herbert, 2022).

The effect of FA on social acceptance extends across the lifespan. Approximately one-third of food-allergic adults worry about FA-related bullying (Knibb et al., 2024). A study found that adults with FAs tended to actively hide their diagnosis from others in an attempt to be seen as normal, or to avoid being pitied by others (Scherman et al., 2002).

## **Disordered Eating**

Patterns of dietary restriction are a hallmark feature of eating disorders (Jafri et al., 2021). The DSM-5-TR characterizes eating disorders as a "Persistent disturbance of eating or eating-related behaviors that results in the altered consumption or absorption of food and that

significantly impairs physical health or psychosocial functioning" (APA, 202, p. 371). Therefore, it is unsurprising that FA was "overwhelmingly associated" with the prevalence of eating disorders and disordered eating behaviors in a comprehensive review of the literature (Jafri et al., 2021). Dietary restriction and avoidance are the prescriptions for FA management, suggesting that the very behavior safeguarding the patient with FAs from an allergic reaction may be the same behavior putting them at risk for eating disorder vulnerability. The same literature review found disordered patterns of dietary restriction in FA to have "Evolved as a mechanism for avoiding undesirable consequences" (Jafri et al., 2021). This same predicament appears in the management of diabetes, another chronic disease that requires consistent food monitoring. According to the National Institute for Diabetes and Digestive and Kidney Diseases (2021), nearly 20% of individuals with diabetes may have comorbid eating disorders. Similar to FA, it is theorized that one mechanism for the increased eating disorder vulnerability in diabetes is the increased attention and monitoring of food intake (NISSK, 2021). In combination with these strict dietary modifications required by a FA diagnosis, it is theorized that body image disturbance may also contribute to eating disorder vulnerability in FA (Jafri et al., 2021).

## **Body Image Disturbance**

Research suggests a strong association between FA and body image disturbance (Jafri et al., 2021). In a comprehensive review of the literature, individuals with FAs were found to routinely internalize their diagnosis as a "Stable facet of their identity" (Jafri et al., 2021). Rather than seeing themselves as having a chronic disease, they conceptualized their FA as an "intrinsic defect" (Marklund et al., 2007), resulting in feelings of inadequacy and insufficiency (Peniamina et al., 2014). In one study of adolescents, the participants believed there was something fundamentally wrong with their bodies, using words like "short-circuit" or "mistake" (Marklund

et al., 2007). This sentiment was echoed in an adult study, where participants again described their food-allergic bodies as "defective" (Peniamina et al., 2014). Such examples reveal the potential for FA to have an adverse effect on self-concept and self-worth. Based upon this collective literature, Jafri et al. (2021) proposed body image disturbance as a potential mechanism for eating disorder vulnerability in FA (see Figure 2). Of note, this model may only accurately reflect Anorexia Nervosa and Avoidant/Restrictive Food Intake Disorder (ARFID). Further research is necessary to explore the connection with Bulimia Nervosa and other eating disorders (Jafri et al., 2021).

Figure 2

Proposed Mechanism for Development of Eating Disorders Mediated by Body Image

Disturbance as A Result of Food Allergy



Note. From (Jafri et al., 2021).

## **Psychosocial Impact of Anaphylaxis**

The most commonly reported symptom of FA-related psychological distress is anxiety about having an allergic reaction (Knibb et al., 2024). Anaphylaxis is shown to compound the already well-established psychological and socioemotional burdens of routine FA management. The risk of anaphylaxis, the occurrence of anaphylaxis, and the response to anaphylaxis have been associated with significant psychological impacts. Although anaphylaxis is not independently a direct risk factor for the development of a psychiatric disorder, it has been found to be a reliable indicator for determining risk of psychological distress (Feng & Kim, 2019; Herbert & Dahlquist, 2008). Further, food-allergic young adults who have experienced a food-induced anaphylactic reaction report greater worry about their chronic condition, and self-report their food allergies as being more severe than those of peers who have not experienced anaphylaxis (Herbert & Dahlquist, 2008). This is significant because research suggests that a food-allergic person's subjective interpretation of the severity of their allergy may also be an important predictor of psychological distress (Herbert & Dahlquist, 2008).

The DSM-5-TR directly identifies anaphylactic shock as a life-threatening medical emergency that qualifies as a Criterion A traumatic event for the diagnosis of PTSD (APA, 2022). Posttraumatic stress symptoms (PTSS) have been found to be a common consequence of anaphylactic shock (Chung et al., 2011; Tal et al., 2019). In a cross-sectional study of ninety-four anaphylactic shock survivors, 12% met the diagnostic criteria for full PTSD post-anaphylaxis, while 43% met the diagnostic criteria for partial PTSD (Chung et al., 2011, p. 398). In a similar study of 203 adult anaphylaxis survivors in Korea, 41.4% met criteria for a diagnosis of PTSD (Lee et al., 2020). The development of PTSD was not predicted by the severity of the anaphylaxis event (Lee et al., 2020). These findings were reflected in a pediatric study, where

children who had experienced an anaphylactic reaction had significantly higher rates of PTSS than children who had not (Weiss & Marsac, 2016).

Psychiatric comorbidities are mediators in the use of healthy coping strategies across the food allergy community (Chung et al., 2011). As the severity of PTSD symptoms increases post-anaphylaxis, the more likely it is for those individuals to use problem, emotion, and avoidance-focused coping strategies in the future (Chung et al., 2011).

Although fatal food-induced anaphylaxis is rare, the potential of suffering a life-threatening allergic reaction can be distressing (Warren et al., 2020), especially as anaphylaxis-related hospitalizations continue to rise (Dyer et al., 2015). Considering that nearly 40% of food-allergic children and 38% of food-allergic adults have experienced anaphylaxis, a more in-depth understanding of the psychosocial consequences of severe allergic reactions is warranted (Gupta et al., 2018).

# **Addressing Psychosocial Burdens**

Despite the well-established psychological and socioemotional burdens of allergic disease management, there are limited resources in place to support this population. The unmet needs of the FA community were highlighted in the recently published Global Access to Psychological Services (GAPS) for Food Allergy study (Knibb et al., 2024). In the U.S. sample, 67.2% of adults and 76.5% of caregivers endorsed distress related to their or their child's FA; Yet, less than half were screened for FA-related distress during an A/I appointment (Knibb et al., 2024). Only 35.1% had sought mental health services for FA-related distress (Knibb et al., 2024). The most commonly reported barriers to seeking treatment included cost, lack of insurance coverage, a doctor not providing a referral, and a practitioner not being available in the area (Knibb et al., 2024).

The 2020 AAAAI conference noted the insufficient number of FA-informed mental health clinicians capable of working with this population (Herbert & Dunngalvin, 2021). There are limited professionals and resources for allergists to refer their patients to (Herbert & Dunngalvin, 2021). The academy also called for the development of new screening measures for the assessment of FA anxiety, eating disorder vulnerability, and post-anaphylactic traumatic stress (Herbert & Dunngalvin, 2021). It was suggested that practicing a more interdisciplinary model of allergy and immunology care, by integrating health psychologists into the A/I specialty clinics, would better serve the needs of the FA patients (Herbert & Dunngalvin, 2021).

Psychosocial burdens of allergic disease are starting to be addressed. In 2022, the Children's Hospital of Philadelphia published the Scale of Food Allergy Anxiety (SOFAA) as the first condition-specific measure of anxiety for children and parents in this population (Dahlsgaard et al., 2022). The Division of Allergy and Immunology at National Children's Health Care System in Washington, D.C., practices multidisciplinary healthcare by having mental health professionals in the exam room during OFCs. The Food Allergy Counselor Directory is the first and only catalog of FA-informed mental health providers in the United States who self-declare as having FA knowledge. The directory is available to professionals and patients alike who are looking to connect with licensed clinicians who have this area of expertise. Although limited, resources for mental health providers without FA knowledge are also becoming available. For example, one theoretical model of emotion-focused therapy (EFT) was presented as a modality for treating PTSS in food-allergic adults following an anaphylactic reaction (Taylor & Lewis, 2018). Dahlsgaard, Lewis, and Spergel (2023) recently published a proof-of-concept study on an outpatient manualized cognitive-behavioral treatment protocol for children with FA-related anxiety called Food Allergy Bravery. Further, the Academy for Food

Allergy Counseling (AFAC) provides educational and networking opportunities for licensed providers interested in improving their competency level in this area of practice.

# Anxiety, or Anaphylaxis?

The purpose of this section is to integrate the previously articulated literature on food allergy, human stress responses, Polyvagal Theory, and fear learning to provide a rationale for the intended research question.

# **Differentiating Anxiety from Medical Emergencies**

Emergency department (ED) utilization for anxiety-related conditions is high. Research suggests that 0.93% of annual ED visits are due to anxiety, rather than life-threatening medical emergencies (Dark et al., 2017). It is hypothesized that anxiety is treated more frequently in EDs than any other mental health condition due to its acute somatic symptomatology (Dark et al., 2017). It is estimated that the annual healthcare cost of anxiety disorders is \$42.3 billion (Dark et al., 2017). One of the most common presentations of anxiety in EDs is panic attacks related to non-cardiac chest pain (NCCP) (Dark et al., 2017). A hallmark feature of panic attacks is the worry that the somatic symptoms are reflective of a life-threatening illness (APA, 2013). In fact, one study found that 50% of patients with panic disorder sought ED services at least six times (Dark et al., 2017). While the misinterpretation of anxiety as a medical emergency is a well-known phenomenon in healthcare and emergency medicine, it has not yet been specifically explored in the context of FA.

# **Differentiating Anxiety and Anaphylaxis**

Anxiety attacks and anaphylaxis are both acute reactions characterized by physiological and psychological distress. The symptoms commonly associated with these responses are markedly similar. Overlapping symptomology includes increased heart rate, shortness of breath,

difficulty breathing, tightness of the throat, GI distress, and feelings of impending doom. Given their similarities, it can be difficult for a food-allergic person to distinguish an anaphylactic reaction from anxiety-based symptoms (Manassis, 2012).

It can also be difficult for an observer to distinguish an anaphylactic reaction from anxiety symptoms. Evidence suggests that trained medical professionals have struggled to make this distinction in real time. In a case study from the country of Georgia, researchers investigated 79 reports of adverse events following immunization (AEFI) in response to a measles-rubella vaccination campaign. Five children with AEFI were initially given a diagnosis of anaphylactic shock by the provider (Khetsuriani et al., 2010). Through their investigation, four of the five (80%) cases were retroactively identified as vasovagal syncope and/or anxiety attacks, rather than allergic reactions (Khetsuriani et al., 2010). The healthcare providers were unable to effectively differentiate allergic reaction symptoms from anxiety symptoms following immunization in these patients. The Melbourne Vaccine Education Centre recognized similar difficulties and created a *Guidance for Differentiating Anaphylaxis from Acute Stress Response for Vaccine Providers and Emergency Departments* didactic to educate their medical professionals on how to make this intricate distinction (Victoria Department of Health, 2021).

Accurate distinctions are important. While allergists unanimously recommend the prompt administration of epinephrine in response to any suspicion of an allergic reaction (AAAAI, 2022), misdiagnoses can have compounding psychosocial, medical, public health, and financial consequences. This was demonstrated in the Georgia measles-rubella vaccine trial, where misdiagnosed anxiety attacks perpetuated vaccine hesitation (Khetsuriani et al., 2010). From an FA lens, one possible scenario is the discontinuation of an OFC and misdiagnosis of an FA due to anxiety symptoms that mimicked an allergic reaction, leading to unnecessary avoidance of that

food. Another example is recurrent emergency department visits for panic attacks that resemble allergic reactions, burdening families with undue hospital bills.

# Hypothesis

Traumatic events have the potential to alter the human stress response. Such physiological and emotional dysregulation can lead to increased sensitivity to danger cues and interoceptive signals (Schaan et al., 2019; Manassis, 2012; Joshi, Aupperle, & Khalsa, 2023). Traumatic experiences can also adversely affect our ability to interpret changes in our internal homeostasis (Schaan et al., 2019; Manassis, 2012; Joshi, Aupperle, & Khalsa, 2023).

Fear learning helps explain how these mind-body disconnections can perpetuate fear responses about suffering another medical emergency following medical trauma. Through classical conditioning, any detection of bodily changes to homeostasis becomes associated with the traumatic events and is a catalyst for a fear response (Joshi, Aupperle, & Khalsa, 2023). Repeated exposure to reminders of the traumatic event (e.g., autonomic arousal) strengthens the conditioned fear responses.

Fear learning provides the conceptual basis for the hypothesized mechanism that perpetuates somatic trauma responses in survivors of food-induced anaphylaxis following a severe allergic reaction. Routine exposure to both physiological (e.g., autonomic arousal) and contextual (e.g., daily food consumption) triggers that resemble their traumatic event offers repeated opportunities for the strengthening of the conditioned fear responses.

The physiological and psychological symptoms associated with anxiety are markedly similar to those seen in anaphylaxis, making it difficult to differentiate between the two acute reactions (Manassis, 2012). It is hypothesized that physiological and emotional dysregulation in response to trauma, in combination with fear learning, would make it increasingly challenging to

differentiate the overlapping symptomatology following an anaphylactic reaction. While the misinterpretation of anxiety symptoms as a medical emergency is a well-known phenomenon in healthcare and emergency medicine (e.g., non-cardiac chest pain), it has not yet been specifically explored in the context of FA.

# Summary

Approximately 1 in 10 (11%) adults and 1 in 12 (8%) children in the United States have a food allergy (Warren, Jiang, & Gupta, 2020). FA management is associated with increased levels of anxiety, depression, and emotional distress (Feng & Kim, 2019). The incidence of food-induced allergic reactions is shown to compound the well-established psychosocial burdens of routine FA management. The DSM-5-TR directly identifies anaphylactic shock as a life-threatening medical emergency that qualifies for a Criterion A traumatic event for the diagnosis of PTSD (APA, 2022). In fact, PTSS has been found to be a common consequence of anaphylactic reactions (Chung et al., 2011; Tal et al., 2019). Traumatic events have the potential to alter the human stress response, perpetuate physiological and emotional dysregulation, and adversely affect our ability to interpret changes in our internal homeostasis (Schaan et al., 2019).

Fear learning helps explain how mind-body disconnections can perpetuate fear responses about suffering a medical emergency (Joshi, Aupperle, & Khalsa, 2023). Given the overlapping symptomatology of the two acute reactions, it can be difficult to distinguish anxiety from anaphylaxis (Manassis, 2012). It may be even more challenging for food-allergic individuals to differentiate the symptoms following an allergic reaction, due to disruptions in the mind-body feedback loops. The investigation intends to capture and describe the shared lived experiences of the food-allergic young adults as they attempt to differentiate anxiety symptoms from anaphylaxis symptoms in the aftermath of a severe allergic reaction.

## **Chapter 3: Research Design and Methodology**

This study aims to capture and describe the shared lived experiences of food-allergic young adults as they attempt to differentiate anxiety symptoms from anaphylaxis symptoms in the aftermath of medical trauma. In order to decipher the collective meaning of their experiences, a mixed-methods research design was indicated. The purpose of this chapter is to provide a rationale for the chosen theoretical framework and outline the research design and methodology. The sections are as follows: Chapter Overview, Research Design, Population and Sample, Measures, Procedures, Data Analysis, Validity, Limitations, and Ethical Assurances.

The guiding question for the study is as follows: What is the functional impact of posttraumatic stress symptoms (PTSS) on survivors of food-induced anaphylactic shock? The study is further grounded by two subquestions:

- 1. What is the experience of food-allergic young adults in distinguishing anxiety symptoms from anaphylaxis symptoms?
- 2. How do food-allergic young adults attempt to distinguish anxiety symptoms from anaphylaxis symptoms, and is it effective?

## **Research Design**

This investigation took a mixed-methods approach to understanding the subjective experience of food-allergic young adults following anaphylaxis. According to Kazdin (2017), mixed methods designs are complementary approaches to psychological research because "Qualitative data brings the quantitative data to light and provides poignant meaning to the numbers" (p. 239). A combination of quantitative and qualitative data collection broadened our understanding of the shared lived experiences of this population.

Quantitative data collection followed an observational research design. Observational research is used to assess existing participant characteristics, rather than the direct manipulation of conditions (Kazdin, 2017). Observational research designs are used to answer questions about intact groups. Intact groups are a collection of individuals who inherently share a common characteristic (e.g., mental health diagnosis, exposure to a specific event) that is not randomly assigned by the investigator (Kazdin, 2017). In this study, the observational research design was used to gather prevalence/incidence data about FA and mental health from the participants (Kazdin, 2017).

Qualitative data collection followed a phenomenological research design.

Phenomenology is a qualitative research method that captures the universal essence of a concept through first-person recollections of the experience (Creswell & Poth, 2017). Phenomenological research gathers individuals who have experienced that phenomenon and identifies similarities amongst their shared lived experiences (Creswell & Poth, 2017). By exploring what the participants' experiences have in common, the phenomenological researcher can attempt to decipher the collective meaning of the phenomenon (Creswell & Poth, 2017). In this study, the phenomenological approach served to personify the stories of anaphylaxis survivors and craft a composite description of their experiences (Creswell & Poth, 2017).

### **Population and Sample**

## **Population**

The population, or the larger community to which the results of this investigation may be generalized, is young adults (ages 18 to 29) who have experienced an anaphylactic allergic reaction due to an IgE-mediated food allergy.

### Sample

A convenience sample of participants was selected from the defined population for participation in this study. According to Creswell and Poth (2017), the sample size for phenomenological research designs may range from three to fifteen participants.

### **Inclusionary Criteria**

Both observational and phenomenological research require a sample of individuals who have each experienced the identified phenomenon (Kazdin, 2017; Creswell & Poth, 2017).

Therefore, participants must have met the identified inclusionary criteria to be eligible to participate in this study. For the purposes of this study, inclusionary criteria differed based on the phase of data collection.

To be eligible to participate in this study, participants must have met the inclusionary criteria outlined in the Screening Questionnaire. Participants must have endorsed at least one physician-diagnosed, IgE-mediated food allergy. Participants with *only* food intolerances or self-imposed dietary restrictions were excluded from the sample. Further, those with *only* non-IgE mediated allergies (e.g., food protein-induced enterocolitis syndrome [FPIES]) were excluded from the sample. Individuals with commonly comorbid atopic conditions (e.g., eosinophilic esophagitis, atopic dermatitis, etc.) in addition to at least one IgE-mediated food allergy were eligible to participate. All participants must have received medical attention for at least one food-induced anaphylactic reaction within the past year. For the purposes of this study, medical attention was defined as "Use of an epinephrine auto injector (e.g., EpiPen, Auvi-Q), an emergency medical screening (e.g., emergency room, urgent care, 911), and/or the prescription of rescue medications from your doctor (e.g., steroids)." This timeline was selected to ensure the experience of the identified anaphylactic reaction (IAR) was within recent memory.

This study included a semi-structured qualitative interview. To be eligible to participate

in the Interview component of this study, participants must have met the inclusionary criteria in the Screening Questionnaire *and* endorsed a history of posttraumatic stress symptoms (PTSS) related to their food-induced anaphylactic reaction during the Survey. For the purposes of this study, the presence of PTSS was operationalized using a total score of > 24 on the Impact of Event Scale - Revised (IES-R).

#### Measures

This study utilized the following measures: Screening Questionnaire, Survey, and Impact of Events Scale - Revised (IES-R) (see Appendix).

## **Screening Questionnaire**

The purpose of the Screening Questionnaire was to determine whether participants met the inclusionary criteria to participate in the Survey component of this study (see Procedures). The Screening Questionnaire gathered participant information related to the preliminary inclusionary criteria: (1) Age, (2) presence of at least one IgE-mediated food allergy, and (3) whether they sought medical intervention for a food-induced anaphylactic reaction within the past year (e.g., identified anaphylactic reaction [IAR]). The Screening Questionnaire was administered to participants online through the SurveyMonkey platform.

# Survey

The purpose of the Survey was to gather background information and participant data related to demographics, allergic disease history, and personal experience with mental health treatment. The Survey utilized a combination of short responses, forced choice, and Likert scale response styles. The Survey was administered to participants online through the SurveyMonkey platform.

## **Impact of Event Scale - Revised (IES-R)**

## Background

The Impact of Event Scale - Revised (IES-R) is a 22-item self-report measure for the DSM-4 that assesses subjective distress resulting from a traumatic event (Weiss & Marmar, 1996). The scale is designed to differentiate a variety of traumatized groups from non-traumatized groups in the general adult population (Weiss & Marmar, 1996). This tool measures three dimensions of the human stress response: Intrusion, Avoidance, and Hyperarousal (Weiss & Marmar, 1996). Confirmatory factor analyses have supported this three-factor solution (Beck et al., 2008). The IES-R demonstrates strong internal consistency (Cronbach's alpha = 0.96) and convergent validity, as it correlates with other validated measures of PTSS and PTSD (Creamer, Bell, & Failla, 2003).

### Utilization

The IES-R is one of the most widely used measures of PTSS (Weiss, 2007). It has been validated and utilized across a variety of diverse populations and has been translated into more than twenty languages. Notably, the IES-R is one of the self-report PTSD screening measures used by the National Center for PTSD and the U.S. Department of Veterans Affairs, evidencing its prominence in the field of psychology. Efficacy studies have demonstrated the utility of the IES-R following a range of traumatic events, including medical events like anaphylactic shock. Two recent studies published in the Allergy, Asthma, and Immunology Research journal used the Korean version of the IES-R (IES-R-K) to assess PTSS in patients and caregivers following acute anaphylaxis (Jeong et al., 2022; Lee et al., 2020). Based on its psychometric properties, cross-cultural validity, and previous utilization in anaphylaxis research, the IES-R was selected to operationalize PTSS in this research study.

## **Operationalization**

To be eligible to participate in the Interview component of this study, participants must have endorsed a history of PTSS related to an acute food-induced anaphylactic allergic reaction within the past year. The presence of PTSS was operationalized utilizing the IES-R. All 22 items of this measure are ranked on a 5-point Likert scale (0, Not at all; 1, A little bit; 2, Moderately; 3, Quite a bit; 4, Extremely). According to Weiss and Marmar (1996), participants with a Total Score of 24-32 are at risk of meeting criteria for PTSD (e.g., "Partial PTSD") as outlined by the DSM-4. Total Scores >33 are indicative of the likely presence of PTSD (e.g., "Probable PTSD") as outlined by the DSM-4. Of note, the IES-R is not meant to be an independent diagnostic tool. Using standards presented by Weiss and Marmar (1996), the presence of PTSS following the IAR was operationalized by a score of > 24 on the IES-R.

In addition to the Total Score, the IES-R reports three subscales: Intrusion, Avoidance, and Hyperarousal. According to Weiss and Marmar (1996), the Intrusion subscale addresses symptoms related to intrusive thoughts, nightmares, intrusive feelings and imagery, and dissociative-like reexperiencing. The Avoidance subscale addresses symptoms of numbing responsiveness and the avoidance of feelings, situations, and ideas (Weiss & Marmar, 1996). The Hyperarousal subscale addresses symptoms related to anger, irritability, hypervigilance, difficulty concentrating, and a heightened startle response (Weiss & Marmar, 1996). There are no psychometrically accepted cutoffs/thresholds for interpreting the subscale total scores documented in the literature. According to Weiss and Marmar (1996), the average rating given to the items included in each subscale is considered indicative of the level of impairment imposed by those symptoms. The IES-R is not intended to be a diagnostic tool. The guidelines presented by Weiss and Marmar (1996) are as follows: No Symptoms (0), Few Symptoms (1), Moderate Symptoms (2), High Level of Symptoms (3), Extremely High Level of Symptoms (4).

## **Modifications**

Participants were prompted to respond to the IES-R based on their experience in the month following the IAR. This required a modification of the original IES-R instructions, as authored by Weiss and Marmar (1996). The original scale states, "Please read each item and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to \_\_\_\_, how much were you distressed or bothered by these difficulties?" The modified rephrasing read, "Please read each item and then indicate how distressing each difficulty was for you IN THE MONTH FOLLOWING [identified anaphylactic reaction], how much were you distressed or bothered by these difficulties?"

The modification of the IES-R was intended to better address the aim of qualitative research questions. The specific language and timeframe changes were selected in order to capture symptomatology immediately following the IAR. For this phenomenological study, it is not required for participants to be actively experiencing PTSS. Rather, this study sought to reflect on the participants' lived experiences of PTSS when they were present sometime over the past twelve months. This timeline kept the IAR within the participant's recent memory, while still offering a wide enough time frame to support the sampling goal. Previous research studies have also adapted the IES-R for this purpose. In the Korean-based study of patients and caregivers following acute anaphylaxis, the time interval between the IAR and the administration of the IES-R-K ranged from 10 to 102 days (Lee et al., 2020).

#### **Procedures**

### Recruitment

Paper copies of the recruitment fliers were distributed to an allergy and immunology practice based in Chicago, Illinois, which agreed to post the flier in their offices. Virtual

recruitment fliers were posted to social media (e.g., Instagram, Facebook), shared with permission to special interest groups online (e.g., Spokin Food Allergy App), and sent directly to personal contacts. The recruitment fliers encouraged snowball sampling, where participants were encouraged to pass along the recruitment information to persons they knew who might have qualified and/or been interested. Recruitment fliers provided a quick response (QR) code and digital web address that linked interested participants directly to the study materials.

## **Study Questionnaire**

The Study Questionnaire of this study was conducted online via the SurveyMonkey platform. The Study Questionnaire included: Screening Questionnaire, Informed Consent, Survey, IES-R, Contact Information, and Resources.

## Screening Questionnaire

The Screening Questionnaire assessed participant eligibility for this study (see Measures). Participants who did not meet the inclusionary criteria were directed to the Resource page. Participants who met the inclusionary criteria were directed to proceed with the study in the SurveyMonkey platform.

## **Informed Consent**

In the Informed Consent component of this study, participants were informed of the purpose and nature of the study, research procedures, description of foreseeable risks and benefits, and limits to confidentiality. Participants were provided with contact information for the PI to answer any additional questions. Participants who withheld consent were directed to the Resource page. Participants who gave informed consent were directed to the Survey page.

### Survey

The Survey gathered data from participants related to demographics, allergic disease history, and mental health treatment (see Measures). Participants who opted out of providing this background information were directed to the Resource page. Participants who completed the Survey were directed to the IES-R page.

### IES-R

The Impact of Events Scale - Revised (IES-R) was used to operationalize the presence of PTSS (see Measures). Participants completed the IES-R based on their experiences in the one month following the IAR. Participants who opted out of the IES-R were directed to the Resource page. Participants who completed the IES-R and scored < 24 were directed to the Resources page. Participants who completed the IES-R and scored > 24 were directed to the Contact Information page.

## **Contact Information**

The Contact Information page requested a valid email address from participants who were interested in participating in the qualitative interview phase of this study. Participants were prompted with the following message:

Thank you for completing this survey. If you are interested and willing to participate in a short, virtual interview about your food allergy / mental health experiences, please provide your email address below. By providing my email address below, I permit the primary investigator to contact me via email about further participation in this research study. I understand that by providing my contact information, the previously answered questions will be tied to my email address, and therefore, will no longer be anonymous. Participants who opted out of providing contact information were directed to the Resource page.

Participants who provided their email address were directed to the following statement: "Thank

you for your continued interest in this study. The primary investigator may contact you at the email address you provided about further participation. For questions, please contact Alyssa Bauder, MA, LPC, at abauder@ego.thechicagoschool.edu." Participants were then directed to the Resource page.

#### Resources

The Resources page connected participants with relevant FA and mental health resources and provided contact information for the PI (see Appendix D). All participants who entered the Study Questionnaire were directed to the Resources page at the conclusion of their participation, regardless of whether they opted out or reached the endpoint.

### **Interview Phase**

The Interview Phase of this study was conducted virtually and occurred at a separate time from the Study Questionnaire. The Interview Phase of this study included: Contacting Participants and conducting interviews.

### **Contacting Participants**

Participants who provided a valid email address were contacted by the lead investigator.

Participants were emailed the following message:

Thank you for your participation and continued interest in this study. If you are still interested and willing to participate in a short, virtual interview about your food allergy / mental health experiences, please respond with your preferred time slot(s). The interview is estimated to take approximately one hour and will be conducted virtually via Zoom.

Please do not hesitate to contact me with any further questions.

Included in the email, participants were offered a range of virtual interview time slots based on the lead investigator's availability. Qualitative interviews took place on a rolling basis. Once

participants chose their preferred interview time slot, a confirmation email with the scheduled Zoom meeting web address was sent by the PI.

#### Interview

According to Creswell and Poth (2017), data collection in phenomenological research typically involves an interview with the participant. Therefore, to capture the subjective interpretation of their lived experiences, the participants were led through a semi-structured interview. All qualitative interviews were conducted virtually through the HIPAA-compliant video conferencing platform, Zoom. The duration of the interviews ranged from twenty to thirty minutes. The following prompts were posed in the interview: (1) What has been your experience in distinguishing between anxiety symptoms and anaphylaxis symptoms since your most recent allergic reaction?, and (2) What has affected your ability to differentiate between the two?

The interviews were audio-recorded. Participants were first notified of this requirement during the informed consent process. Participants were also prompted to accept or decline recording at the initiation of the Zoom interview. The recorded audio files were saved using a pseudonym to protect participant identity. Transcriptions of the recorded audio files were created simultaneously via Zoom. Transcriptions were saved using a pseudonym to protect participant identity. All recorded materials were destroyed following transcription.

# **Conclusion of Data Gathering**

The study recruited participants from August 2024 until April 2025. The study gathered Study Questionnaire data until a total of five qualitative interviews were completed in the Interview Phase. After the five qualitative interviews were completed, data gathering was considered complete, and the online SurveyMonkey questionnaire was disabled.

### **Data Analysis**

## **Quantitative**

The mixed methodology of this study required the quantitative and qualitative data to be processed and analyzed separately. Quantitative data was exported to and analyzed in SPSS.

Descriptive statistics were used to inform the main research question.

### **Oualitative**

Qualitative interview data processing was conducted with NVivo, a digital software often used in the social sciences for the organization and analysis of qualitative research data. NVivo was utilized for the systematic detection of common themes across participant interview transcriptions. NVivo assisted in the evaluation and interpretation of the underlying structure of the target phenomenon.

Qualitative data processing followed the systematic procedures and guidelines of psychological phenomenology proposed by Dr. Clark Moustakas (1994). Horizontalization, a term coined by Moustakas (1994), was the first step in phenomenological analysis of this data set (Creswell & Poth, 2017). Horizontalization is an organizational strategy that tasks researchers with pulling "significant statements" from participant responses (Moustakas, 1994; Creswell & Poth, 2017). All five transcripts were reviewed by the PI, and key quotes were highlighted. Next, a systematic analysis of these statements can identify overarching themes, also referred to as "clusters of meaning" (Creswell & Poth, 2017). Using NVivo, the PI created a series of parent codes and child codes to identify themes and subthemes within the data that addressed the underlying research questions.

Descriptions of the participants' lived experiences can be either textural and structural (Creswell & Poth, 2017). Textural descriptions articulate *what* the participant directly experienced, while structural descriptions speak to *how* the participant experienced the

phenomenon (Creswell & Poth, 2017). To craft a composite description of their experiences, the PI identified and coded both the content and the context of participant experiences in NVivo (Creswell & Poth, 2017). The integration of textural and structural descriptions informs the overall essence of the phenomenon (Creswell & Poth, 2017).

Composite descriptions represent the underlying structure of the experience (Creswell & Poth, 2017). The PI synthesized the themes and subthemes, and the textural and structural descriptions, to interpret the core meaning of the phenomenon.

### Validity

Standards of validation and evaluation followed the guidelines proposed by Kazdin (2017) and Creswell and Poth (2017). This proposed study promoted validity through psychometric properties, peer review, and researcher positioning.

## **Psychometric Properties**

Data validity is a measure of the accuracy of information collected in a dataset (Kazdin, 2017). Assessment measures with strong reliability and validity psychometrics were selected to help protect data validity in this study.

### **Peer Review**

This study was assigned a panel of core faculty members to serve as the dissertation committee. The team was available for continued guidance and consultation, offering their expertise in dissertation development, mixed-methods research designs, and health psychology. Frequent collaboration with the chairperson and reader helped improve the quality of the investigation and promote research validity.

## **Researcher Positioning**

Following Moustakas' (1994) philosophy of transcendental phenomenology, the focus of this research should be centered on the experiences of the participants, rather than the interpretations of the researcher. Therefore, to account for my own individual biases about this research topic, the study utilized epoché, or bracketing. Bracketing is a practice in which "Investigators set aside their experiences, as much as possible, to take a fresh perspective toward the phenomenon under investigation" (Creswell & Poth, 2017, p. 78). The term was popularized in philosophy by Edmund Husserl before being adopted by transcendental phenomenology. While Moustakas (1994) traditionally included an entire narrative from the researcher regarding their experiences with the topic, Creswell and Poth (2017) recommend a shortened personal statement in the methods section about the role of the researcher.

In early childhood, I was diagnosed with multiple life-threatening food allergies. My first food-induced anaphylactic reaction occurred at age six, meaning the majority of my life's memories exist in a world post-anaphylaxis. Following a second anaphylactic reaction in high school, I suffered pervasive symptoms of avoidance, hypervigilance, and reexperiencing, and was eventually diagnosed with posttraumatic stress disorder by a licensed clinical psychologist. These experiences not only inspired my career trajectory in the field of psychology, but also inspired the research direction for my doctoral dissertation. Before beginning this project, I took special care to ensure that I was far enough along in my healing journey to pursue this research question. I wanted the exploration to be restorative, rather than triggering or draining. Despite knowing that I had created enough space for myself to take a step back from the topic, my data still had the potential to be collected and analyzed through a biased lens. To help set aside my preconceptions about the lived experiences of the participants, I practiced bracketing by using memo writing during data analysis and by prioritizing regular consultation with my peers and

mentors. By acknowledging and accounting for the preconceived notions I brought to this investigation, I hope to have improved the overall validity of the research study.

#### Limitations

A limitation of this research design was its reliance on self-report data. This study did not involve third-party corroboration of diagnoses from medical and/or behavioral health professionals. Rather, the study relied on independent endorsement from the participants.

Further, due to the scale and funding of this study, it was limited to the collection of a convenience and snowball sample. The sample is not representative of the young adult food allergy population as a whole, and therefore, is limited in its external validity and generalizability beyond the confines of this study. The sample trended towards highly educated white women with access to health care and immunological medical services.

Another limitation of this research design was its reliance on participant memory and recall of traumatic events. The accuracy of memories recalled from traumatic events is highly debated in the literature, and is only further complicated by a diagnosis of PTSD. However, according to a meta-analysis on the accuracy of traumatic memories, the most common pitfall of accurate traumatic memory recall is the passage of time (Mattsson, Sonne, & Carlsson, 2021). Therefore, requiring that the IAR occurred within the past twelve months is thought to help reduce some of the traumatic memory recall fatigue. Such limitations to the study's internal validity were taken into consideration during data analysis and discussion.

#### **Ethical Assurances**

Several potential ethical and legal consequences were considered in the development of this study. Prior to conducting the study, the PI sought university and institutional review board approval for the research design. All utilized materials and instruments have been granted

permission to replicate. As part of the recruitment procedures, all participants completed the informed consent process. Prospective participants were informed of the purpose of the research study, its expected duration, general procedures, and foreseeable benefits. Candidates were informed of their right to decline participation or withdraw from the study at any point in time. No compensation or incentives were offered. Any potential consequences or adverse side effects of participation in the study were disclosed to prospective participants. Given the nature of the research, the hypothesized risk factors included emotional distress, hyperarousal, or reliving of the traumatic events during the semi-structured clinical interview. At the conclusion of their participation, each individual was provided with contact information for the research team and external mental health resources to address any prolonged distress as a result of their participation. Participant information was kept confidential. No identifying information was disclosed. All collected information (e.g., audio recordings, transcriptions, etc.) was stored using pseudonyms and promptly destroyed following the conclusion of the study. Candidates were warned about the limits of confidentiality given the virtual collection of their personal health data.

### **Chapter 4: Results**

This study used a mixed-methods approach to capture and describe the shared lived experiences of food-allergic young adults as they attempt to differentiate anxiety symptoms from anaphylaxis symptoms in the aftermath of a severe allergic reaction. The guiding question for the study is as follows: What is the functional impact of posttraumatic stress symptoms (PTSS) on survivors of food-induced anaphylactic shock? The study is further grounded by two subquestions: (1) What is the experience of food-allergic young adults in distinguishing anxiety symptoms from anaphylaxis symptoms? (2) How do food-allergic young adults attempt to distinguish anxiety symptoms from anaphylaxis symptoms, and is it effective? The purpose of this chapter is to outline and summarize the findings of this research study. The sections are as follows: Participants, Questionnaire Findings, Interview Findings, and Summary.

## **Participants**

### **Study Questionnaire**

The Study Questionnaire included the Screening Questionnaire, Informed Consent, Survey, and IES-R. Seventy-one (n=71) participants responded to the study's recruitment. To be included in this study, participants had to have endorsed the following inclusionary criteria in response to the Screening Questionnaire: (1) aged 18 to 29, (2) presence of at least one physician-diagnosed, IgE-mediated FA, and (3) had sought medical intervention for a food-induced anaphylactic reaction within the past twelve months. Forty-three (n=43) participants met the inclusionary criteria for this study. Twenty-seven (n=27) of the participants consented to participate in the study.

The Survey component of the Study Questionnaire gathered background information and participant data related to demographics, allergic disease history, and personal experience with

mental health treatment. The IES-R component of the Study Questionnaire was used to assess PTSS among the participants. Nineteen participants (n=19) completed all parts of the Study Questionnaire. One participant (n=1) completed the Survey, but did not complete the IES-R.

The majority of participants self-identified as white females (see Figures 3, 4). The highest level of education ranged from less than a high school diploma to a postgraduate degree (see Figure 5). The most commonly endorsed food allergies were peanut, tree nut, and egg (see Figure 6). Of the twenty participants, 80% had experienced three or more lifetime allergic reactions (n=16). Across the nineteen participants (n=19) who completed the IES-R, their average Total Score was 39.95 (SD=22.54) (see Figure 11).

Figure 3

Participant Demographics, Self-Identified Gender

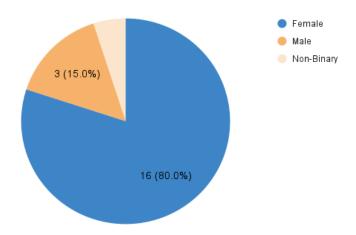


Figure 4

Participant Demographics, Self-Identified Race/Ethnicity

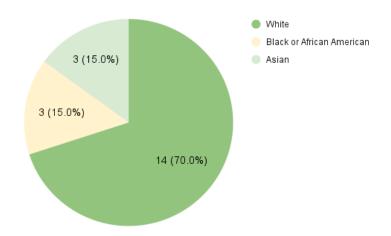


Figure 5

Participant Demographics, Highest Level of Education

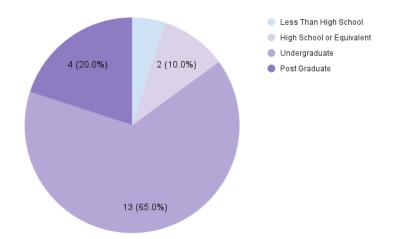
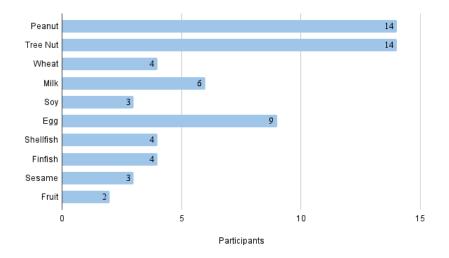


Figure 6

Participant Demographics, Self-Reported Food Allergies



## **Interview**

To be eligible to participate in the Interview Phase of this study, participants had to have a Total Score > 24 on the IES-R during the Study Questionnaire. Of the nineteen participants who completed the IES-R, 68% (n=13) were eligible to complete the Interview component of this study (see Figure 7). Five total participants (n=5) completed a qualitative interview. Four participants self-identified as white females, and one participant self-identified as an Asian female (see Figure 8). The highest level of education ranged from undergraduate to postgraduate (see Figure 8). One hundred percent of the participants had experienced three or more lifetime allergic reactions (n=5). Based on their IES-R score, one participant was considered at risk for "Partial PTSD," and the other four participants were considered at risk for "Probable PTSD" (see Figure 9).

Figure 7

Participants Eligible for Interview, Demographics (n=13)

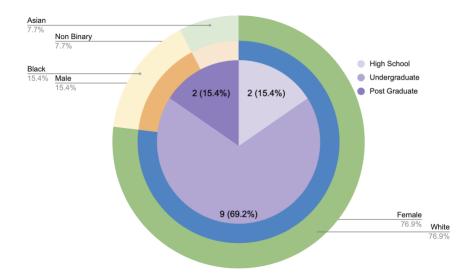


Figure 8

Interview Participants, Demographics (n=5)

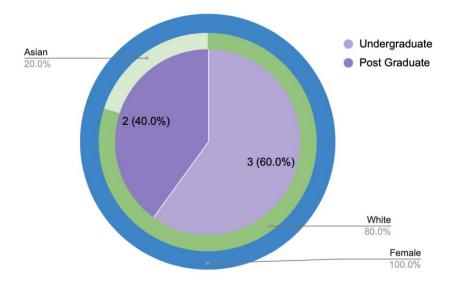
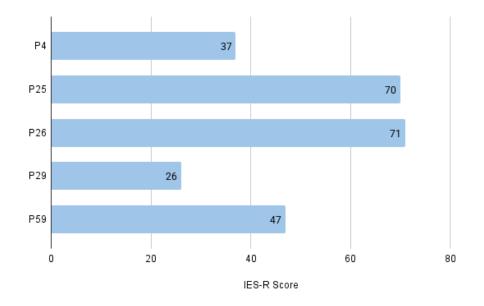


Figure 9

Interview Participants, IES-R Scores



*Note:* The interpretation guidelines presented by Weiss and Marmar (1996) are as follows: No PTSD (<24); Partial PTSD (24-32); Probable PTSD (>33). The IES-R is not intended to be an independent diagnostic tool.

## **Questionnaire Findings**

The Study Questionnaire gathered participant data related to allergic disease history and personal experience with mental health treatment through an online questionnaire.

# **General Mental Health Treatment History**

The history of mental health treatment varied across participants. The operational definitions of mental health treatment that were given to participants during the Survey are outlined in Appendix C. Sixty-five percent of the sample that completed the Survey reported that they engaged in a form of therapy throughout their lifetime (n=13), and 45% of this sample had reported a form of psychiatric medication management throughout their lifetime (n=9). 35% of the sample had never engaged in any form of mental health treatment throughout their lifetime (n=7). Forty-five percent of participants endorsed having been previously diagnosed with an

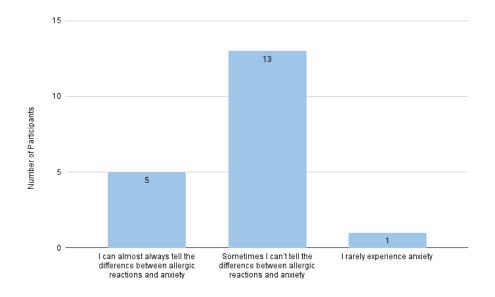
anxiety or anxiety-related disorder (e.g., generalized anxiety, panic disorder, PTSD, acute stress disorder) (n=9). Fifty percent of participants denied having been previously diagnosed with an anxiety or anxiety-related disorder (n=10), and 5% were unsure (n=1).

# **Food Allergy and Mental Health**

Overall, participants endorsed the belief that food allergies had an impact on their mental health. When asked to rate the effect food allergy management has had on their mental health on a ten-point scale (0, no effect; 5, moderate effect; 10, significant effect), the average rating across participants was 7.80 (SD=2.28). Participants endorsed difficulty differentiating between anxiety and anaphylaxis symptoms, with 65% reporting they sometimes cannot tell the difference between the two acute reactions (n=13) (see Figure 10).

Of the Survey participants, 35% have engaged in a form of mental health treatment for a condition related to their food allergy (n=7), while 40% sought mental health treatment for a condition unrelated to their food allergy, but discussed food allergy-related concerns with their provider (n=8). Of the participants who discussed food allergy management in treatment with a mental health provider, regardless of the initial presenting concern, 91% reported that mental health treatment that addressed their FA was beneficial (n=10). Of the participants who have never discussed food allergy management with a mental health provider (n=9), 44% believed they would benefit from mental health treatment related to their food allergy (n=4).

Figure 10
Self-Reported Ability to Differentiate Between Allergic Reactions and Anxiety



## **Posttraumatic Stress Symptoms**

Posttraumatic stress symptoms (PTSS) were assessed using the Impact of Events Scale - Revised (IES-R) during the Study Questionnaire. According to Weiss and Marmar (1996), participants with a Total Score of 24-32 on the IES-R are at risk of meeting criteria for PTSD (e.g., "Partial PTSD") as outlined by the DSM-4. A Total Score of > 33 is indicative of the likely presence of PTSD (e.g., "Probable PTSD") as outlined by the DSM-4 (Weiss and Marmar, 1996). The IES-R is not meant to be a diagnostic tool. Using the standards presented by Weiss and Marmar (1996), the presence of PTSS in this study was operationalized by a Total Score of > 24 on the IES-R. Results are reported as At or Above Threshold (24+) — Including "Probable PTSD" (>33) and "Partial PTSD" (24-32) — and Below Threshold (<24). The sample size for the IES-R data includes nineteen participants (n=19). 68.4% (n=13) of the participants had a Total Score > 24 and were considered At or Above Threshold (see Figure 11). Across those thirteen participants (n=13), their average Total Score was 51.15 (SD = 17.42) (see Figure 12).

Figure 11

Thresholds for Participant Total Scores, Impact of Events Scale - Revised (IES-R)

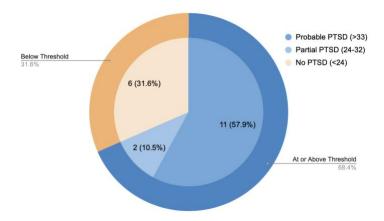
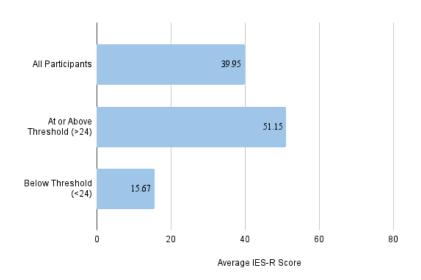


Figure 12

Average Total Score Across Threshold Groups, Impact of Events Scale - Revised (IES-R)



Note. All Participants (SD=22.54); At or Above Threshold (SD=17.42); Below Threshold (SD=8.21).

In addition to the Total Score, the IES-R reports three subscales: Intrusion, Avoidance, and Hyperarousal. According to Weiss and Marmar (1996), the Intrusion subscale addresses symptoms related to intrusive thoughts, nightmares, intrusive feelings and imagery, and dissociative-like reexperiencing. The Avoidance subscale addresses symptoms related to

numbing of responsiveness and the avoidance of feelings, situations, and ideas (Weiss & Marmar, 1996). The Hyperarousal subscale addresses symptoms related to anger, irritability, hypervigilance, difficulty concentrating, and a heightened startle response (Weiss & Marmar, 1996). There are no psychometrically established cutoffs for interpreting the subscale total scores documented in the literature. Therefore, for this study, the subscale total scores are not reported individually. According to Weiss and Marmar (1996), the average rating given to the items included in each subscale is considered indicative of the level of impairment imposed by those symptoms (see Table 1). The IES-R is not intended to be an independent diagnostic tool. The guidelines presented by Weiss and Marmar (1996) are as follows: No Symptoms (0), Few Symptoms (1), Moderate Symptoms (2), High Level of Symptoms (3), Extremely High Level of Symptoms (4).

Based on these guidelines, the level of impairment imposed by PTSS on At or Above Threshold participants was Moderate ( $\bar{x} = 2.33$ ) (see Table 1). Among those same participants, Intrusion symptoms led to the most impairment ( $\bar{x} = 2.45$ , Moderate Symptoms), followed by Hyperarousal symptoms ( $\bar{x} = 2.29$ , Moderate Symptoms), and Avoidance symptoms ( $\bar{x} = 2.25$ , Moderate Symptoms) (see Table 2).

Table 1

Average Item Rating Per Scale, Impact of Events Scale - Revised (IES-R)

	Average Rating $(\bar{x})$				
Scale	All Questionnaire Participants (n=19)	At or Above Threshold (n=13)	Below Threshold (n=6)		
Total	1.82 (SD=0.38)	2.33  (SD = 0.42)	0.71  (SD = 0.45)		
Intrusion	2.04 (SD=0.45)	2.45  (SD = 0.52)	1.14  (SD = 0.42)		
Avoidance	1.53 (SD=0.33)	2.25  (SD = 0.42)	0.52  (SD = 0.24)		
Hyperarousal	1.72  (SD = 0.31)	2.29  (SD = 0.35)	0.50  (SD = 0.36)		

*Note.* An indication of the level of impairment from posttraumatic stress, as presented by Weiss & Marmar (1996). 0 (No Symptoms), 1 (Few Symptoms), 2 (Moderate Symptoms), 3 (High Level of Symptoms), 4 (Extremely High Level of Symptoms).

# **Interview Findings**

The Interview component of this study gathered participant data related to food allergy and mental health experiences of five participants who completed the Study Questionnaire, met criteria for PTSS, and agreed to be interviewed. To capture the essence of the interviewee's attempt to differentiate anxiety symptoms from anaphylaxis symptoms, the qualitative data were analyzed for themes using NVivo. Four major themes with related subthemes were identified. The themes are: (1) Experience of anxiety while attempting to authenticate anaphylaxis symptoms, (2) Tools for differentiating between anxiety and anaphylaxis, (3) Contextual factors that influence the experience of the phenomenon, and (4) Impacts on functioning following a severe allergic reaction. The themes and subthemes are outlined below in Table 2.

Table 2

Interview Themes

Major Theme	Subthemes	
Experience of Anxiety While     Attempting to Authenticate     Anaphylaxis	1a. Overlapping Symptomatology 1b. Thinking Patterns 1c. Behavioral Responses	
2. Tools for Differentiating between Anxiety and Anaphylaxis	2a. Using Physiological Cues 2b. Monitoring Symptom Progression 2c. Stress Reduction 2d. Consultation	
3. Contextual Factors that Influence the Experience of the Phenomenon	3a. Perceived Access to Resources 3b. Baseline Stress Levels	
4. Impacts on Functioning Following a Severe Allergic Reaction	4a. Post Traumatic Stress 4b. Help Seeking	

# Theme 1: Experience of Anxiety while Attempting to Authenticate Anaphylaxis

The participants described an overwhelming sense of anxiety while trying to determine if their physiological symptoms were anxiety-based, the beginning of a life-threatening allergic reaction, or a combination of both. The following subthemes were identified: Overlapping Physiological Symptoms, Thinking Patterns, and Behavioral Responses.

# Subtheme 1A: Overlapping Symptomatology

All participants reported the experience of physiological sensations following the ingestion of a food. The initial symptoms tended to be itchiness, irritation, or a lump sensation in

the mouth, lips, or throat. Other physiological symptoms described included: Shortness of breath; tightening of the throat, with a sense that it was becoming increasingly difficult to swallow; GI symptoms, including nausea and the urgent need to defecate; increased heart rate; and hot flashes. The participants described how they recognized that the physiological sensations were symptomatic of both panic attacks and food-induced anaphylaxis. They described having internal debates with themselves when attempting to distinguish their symptoms. For example, Participant 4 stated,

I was like, does my mouth really itch, or am I just convincing myself that it does?... Am I actually feeling like my asthma symptoms are flaring, or am I just short of breath because I'm anxious? (Participant 4)

All of the participants also acknowledged how the overlapping symptomology of the acute reactions made it increasingly difficult to determine their origin, contributing to a sense of self-doubt in their ability to differentiate them. Participant 4 stated,

We were driving, and everybody was kind of like, 'Is this anxiety or is this a real reaction?' We just don't know...I didn't know. I didn't have a lot of confidence in my ability to tell. (Participant 4)

# Subtheme 1B: Thinking Patterns

All participants described their patterns of thinking while attempting to differentiate between anxiety symptoms and anaphylaxis symptoms. Their cognitions tended to follow patterns of worst-case scenario thinking, jumping to conclusions, and fortune-telling. The participants' thought patterns were described as occurring both in response to physiological disturbances and as the impetus for physiological disturbances. For example, Participant 26

described the physiological symptoms as a "catalyst" for worst-case scenario thinking, while Participant 4 shared the following.

It kind of always starts with this... I'll be eating and I'll be like, 'What if there is something in this?' I'll think that, and then I'll get increasingly anxious. More and more anxious after I have that first initial thought. (Participant 4)

The ruminating thought patterns negatively impacted the participants' ability to appropriately respond to the acute reaction.

It was just an overwhelming lack of control. The anxiety kind of inhibited my normal problem solving skills...My ability to reason in situations like that. It was honestly intense panic over what's going to happen to me. (Participant 4)

While most of the cognitions were panic-driven and action-oriented, some participants identified thinking patterns that minimized their experience. Participant 29 described denying the legitimacy of their genuine anaphylaxis symptoms. Another participant described similar thought patterns due to the fatigue of having these frequent internal debates.

My early reactions in my teen years... It was really hard for me to know I was having a reaction because I was just convinced it was anxiety. I just really didn't want it to be true. (Participant 29)

#### Subtheme 1C: Behavioral Responses

While navigating the physiological sensations and thinking patterns, the participants described their behavior in response to the experience of anxiety. The participants identified the initial five to ten minutes of the discernment process to be the most challenging time to authenticate their symptoms, and consequently, the most anxiety-provoking. In that time period, participants described how they frequently sought out their medications and laid them nearby

(e.g., epinephrine auto-injectors, rescue inhalers, antihistamines). Some stated that they preemptively took antihistamine medications or used their epinephrine autoinjectors, stating it was "better safe than sorry in that situation" (Participant 26). Others described their decision to go to the nearest hospital or emergency room as a precaution. A participant reflected on previously receiving emergency department services for a suspected anaphylactic allergic reaction that was later determined to be a panic attack.

## Theme 2: Tools for Differentiating Between Anxiety and Anaphylaxis

Participants identified a range of tools they use to help differentiate anxiety symptoms from anaphylaxis symptoms. The following subthemes were identified: Physiological Cues, Monitoring Symptom Progression, Stress Reduction, and Consultation.

## Subtheme 2A: Using Physiological Cues

Participants identified non-overlapping symptomatology that could help identify the origin of their acute reactions. Participant 29 referred to these physiological cues as "dead giveaways." Any symptom that could be visually assessed – such as swelling, hives, or rashes – was deemed the most helpful for positively identifying anaphylaxis. Participants described removing makeup, taking photographs of themselves, or recruiting others to help inspect the skin on their faces and hands. Conversely, the absence of such visual cues reassured some participants that the acute reaction was likely from another source, such as anxiety.

I will take selfies of myself on my phone if I'm nervous. I'll smile big or stretch my mouth so you can see my lips clearly. I'll take a photo and then like five minutes later, I'll take another, and five minutes later, I'll take another, if I feel anxious. To kind of prove to myself like 'No, my lip isn't swelling. I can see that there hasn't been any swelling progression.' So that's another thing I do now to kind of differentiate between the anxiety

and the anaphylaxis, and just kind of like calm myself down. It is like some physical proof that says, 'Nope, this isn't changing.' Like my mind can't trick me into thinking my lip is swelling up because I can see that it's not. (Participant 4)

Respiratory symptoms, including wheezing, difficulty breathing, and nasal/sinus congestion, were also frequently endorsed as physiological cues that led participants to positively identify their acute reaction as anaphylaxis.

# Subtheme 2B: Monitoring Symptom Progression

Participants repeatedly described the monitoring of symptom progression as a key tool for differentiating between anxiety and anaphylaxis symptoms. Participants agreed that while symptoms of an anaphylactic reaction would escalate with time, anxiety symptoms would typically decrease with time. Participants endorsed setting timers and/or watching the clock to monitor whether or not their symptoms were intensifying. Participant 26 stated,

I try to keep my eye on the clock... If nothing has continued for X amount of time, then I know it's probably just anxiety or environmental factors, not anaphylaxis. (Participant 26)

The amount of time needed to pass, without an escalation of symptoms, to confirm that the acute reaction was anxiety-based ranged from 15 to 30 minutes from the time the food was ingested.

Consequently, the initial five to ten minutes of the acute reaction were considered by participants to be the most anxiety-provoking and the most challenging to authenticate their symptoms.

## Subtheme 2C: Stress Reduction

Participants employed a variety of stress reduction tools to improve their ability to navigate an acute reaction, regardless of the origin of their symptoms.

I try to do deep breathing to calm down either way because I know that if I'm in a state of heightened anxiety, it's going to make it much harder to figure out what's going on. So I do what I can to calm down. (Participant 4)

Participants described the use of both relaxation-based (e.g., deep breathing, essential oils, walking/getting fresh air) and distraction-based (e.g., listening to music, changing the subject of conversation) techniques for stress reduction. These tools were considered especially valuable when used concurrently with timekeeping to help participants more comfortably wait out the 15 to 30 minutes of symptom monitoring. Several participants described drinking water as a valuable stress reduction tool in these scenarios. Not only did drinking water serve to calm and physically cool the participants off, but it was perceived as a way to cleanse the mouth/throat, and offered repeated opportunities to assess the tightness of the throat when swallowing.

#### Subtheme 2D: Consultation

Participants noted that they repeatedly sought consultation from others while attempting to differentiate between anxiety and anaphylaxis. This consultation was described as more than reassurance or stress reduction. Participants found that getting a second opinion felt anchoring, and could serve as a type of "reality check" (Participant 26). They recruited others to check for any visible symptoms and asked for advice about how to proceed. Participants were selective in who they consulted. Most frequently, they reached out to trusted friends and family members. Some participants contacted their physician or an acquaintance who was a medical professional. Participants preferred to consult with someone who was familiar with food allergies and would not exacerbate an already anxiety-provoking situation. Participants were less likely to alert strangers or peers with whom they were not close.

### Theme 3: Contextual Factors that Influence the Experience of the Phenomenon

Several contextual factors influenced the participants' experience of attempting to differentiate between anxiety symptoms and anaphylaxis symptoms. The following subthemes were identified: Perceived Access to Resources, and Baseline Stress Levels.

#### Subtheme 3A: Perceived Access to Resources

Perceived access to resources impacted participants' experience of anxiety while attempting to authenticate anaphylaxis symptoms. The most desired resources were (1) available rescue medications, (2) seamless access to emergency department services, and (3) connection to social support. Their interpretations of what constituted increased or decreased access to these three resources were subjective, and therefore, differed greatly across the participants. For example, while some were comforted by urban settings because of the increased number of medical facilities, others were distressed by a city's increased traffic patterns and longer commutes to an emergency room. Similarly, while some participants believed being at home offered increased access to resources, others believed it decreased access.

The other thing I've noticed when I'm at home I actually tend to be more stressed for some reason. I think it's because I'm in an apartment, kind of trapped, and it means that if I need help, I'm going to need to kind of pick up the phone and call an ambulance, or I'm going to need to leave my apartment. I'm only relying on my partner, or on myself if I'm alone. (Participant 59)

I would say being at home is a little bit easier because I have everything I need with me...I have two EpiPens in my purse that is next to me...And I know that there's Benadryl in the other cabinet. So it's like an ease of mind. Versus...If I'm in public and

start having an issue, there's more anxiety. Like, I don't have everything that I could ever need with me right now. (Participant 26)

Regardless of their subjective interpretation of access to resources, the most desired resources were consistent across participants.

#### Subtheme 3B: Baseline Stress Levels

Baseline stress levels played a role in the participants' experience of the phenomenon.

They described how increased stress levels made it more likely for participants to have anxiety-based reactions, made it more difficult to differentiate between anxiety and anaphylaxis, and increased the severity of anxiety symptoms while attempting to authenticate anaphylaxis symptoms. Baseline levels of stress were heightened when participants were in new or unfamiliar circumstances. They described increased anxiety when eating at new restaurants, ordering a new dish, and trying a new food. Unfamiliar social situations also increased anxiety for participants.

The added layer of social anxiety, and being in this big scenario where I don't know a lot of people. I was one of the youngest members....I feel like that fueled that sense of anxiety. And honestly, I feel like it worsened my symptoms, too. Just like suffering by myself. And also, of course, with anxiety, the impending sense of doom, like it's really hard to parse that out when you're feeling like, 'Oh, something could be wrong. And I feel like I can't tell anyone about it. And I am spiraling.' It's really easy to just go to the worst case scenario being alone in that. (Participant 29)

## Theme 4: Impacts on Functioning Following a Severe Allergic Reaction

Participants endorsed significant impacts on their day-to-day functioning in the aftermath of a severe allergic reaction. The following subthemes were identified: Posttraumatic Stress and Help-Seeking Behaviors.

#### Subtheme 4A: Posttraumatic Stress

Participants repeatedly endorsed symptomology consistent with that of posttraumatic stress. Participants described avoidance behaviors, hypervigilance, intrusive symptoms, and negative cognitions related to a previous anaphylactic allergic reaction. They reported nightmares, panic attacks, re-experiencing, fatigue, and a loss of trust in themselves and others in the aftermath of an anaphylactic reaction. The participants described how they tended to be overly cautious about their food choices, and engaged in excessive safety behaviors beyond what was considered medically necessary. Participants expressed significant difficulty or an outright refusal to dine outside of the home following an allergic reaction, even at establishments they considered to be safe. Participant 25 reported not consuming enough food in the months following an anaphylactic reaction because she was "too scared to eat."

I still don't feel comfortable going to restaurants. It is super nerve wracking. I feel the need to ask the same question over and over and over again if I do. I haven't tried anything new. I'm very much a person who loves to cook despite my allergies. And before that happened in November, I was trying out all these different recipes. I was like, 'Oh, I want to do a gluten-free sourdough starter. I want to do all these things.' But now... I don't want to try a product that I've never had before. Even if the ingredients are safe. I don't want to try new recipes, even if everything is something I've cooked with. I am rechecking spices that I've already used. I look at these different things that I do eat, and I'm rereading the ingredients in case they did change. And it's obsessive. It's not like, 'Oh, I'm being cautious.' No. I'm totally aware I am being obsessive about it. (Participant 26)

Participants acknowledged feelings of guilt and shame after an allergic reaction. There were themes of self-blame, minimization or invalidation of the suffering, and feelings of isolation. Participants often expressed a sense of impatience or frustration with the healing process, assuming that they should have made more progress in the amount of time that has passed.

It also feels dramatic...I've heard of people having similar [symptoms] for car accidents...I wasn't in a car accident. I didn't go overseas and have to fight. But I'm still getting these weird [symptoms] similar to people who have gone through stuff like that. So it almost feels dramatic and ridiculous...It's a little frustrating because I also am trying to navigate how to basically get over that. But it turns out that it is a difficult process. And there's not a lot of [resources] about it. Like I said, there are things for people who have gotten into car crashes or witnessed something really bad. I don't really see anything for a situation like what I went through. (Participant 26)

One participant described phantom pains in the three injection sites used for emergency medication administration during her most recent anaphylactic allergic reaction.

## Subtheme 4B: Help-Seeking Behaviors

Following an allergic reaction, participants requested support from their physicians.

Participants sought new forms of medication that were thought to help reduce some of the burden associated with allergic disease management. For example, two participants struggling with posttraumatic stress described how they self-advocated to be prescribed Xolair<sup>TM</sup> following an anaphylactic reaction. Xolair<sup>TM</sup> is an injectable biologic that reduces histamine release and is known to increase the threshold required to induce an allergic reaction. Both participants agreed that the reduced risk of having another anaphylactic reaction decreased their overall sense of anxiety related to food allergy management (e.g., traveling, dining out, and eating foods prepared

by others). Similarly, Participant 25 shared how she now prefers carrying Neffy<sup>TM</sup> – the first FDA-approved epinephrine nasal spray for the emergency treatment of allergic reactions – because the needle-free alternative is "not as scary as an EpiPen<sup>TM</sup>" (Participant 25).

Following an allergic reaction, participants also sought support from mental health professionals. Participant 25 described how working with a food allergy-informed psychologist helped her build insight into the impact of food allergies on mental health and helped her develop stronger coping skills for managing anxiety. Participant 4 also engaged in cognitive behavioral and exposure-based treatments to address her symptoms. However, others struggled to get connected with appropriate resources. Several participants highlighted the lack of food allergy-informed mental health resources available in the community and acknowledged the overall sense of isolation with allergic disease management.

I've even asked my doctor if there were any resources, or maybe a counselor that would be specialized, and he didn't know anything. Which I think is quite sad because he's obviously dealing with a lot of children as well, and they would definitely benefit from that...I've gone to therapy before for other topics, and I've never brought up allergies....And then this happened. And then I was like, 'Okay, I should seek it again.' And I really just found a real challenge in terms of nobody was trained on that particular thing...[Food allergy support groups] were not that helpful because the communities are usually led by parents, and they're extremely anxious. So, I've had to kind of remove myself from support groups because of that. I feel a bit alone with it a lot of the time. (Participant 59)

### **Chapter 5: Discussion**

The purpose of this chapter is to address the meaning of the research findings, discuss the limitations and generalizability of the study, highlight the clinical implications, and propose future directions for the research. The sections are as follows: Interpretation of Findings, Limitations, Clinical Implications, Future Directions, and Conclusion.

# **Interpretation of Findings**

# **Guiding Research Question**

The guiding research question for this study was to understand the functional impacts of posttraumatic stress symptoms (PTSS) on survivors of food-induced anaphylaxis. The study was grounded in the hypothesis that anaphylaxis – as a medically traumatic event – could perpetuate brain-body disconnections (e.g., decreased interoceptive accuracy, increased sensitivity to interoceptive signals) that would make it more challenging to differentiate between the overlapping symptomatology of anxiety and anaphylaxis. Routine exposures to physiological and contextual triggers (e.g., daily food consumption) resembling the medically traumatic event were thought to be a mechanism for strengthening interoceptive hypervigilance and the resulting conditioned fear responses.

The findings were consistent with the literature's conceptualization of anaphylaxis as a medically traumatic event. As defined by the thresholds presented by Weiss and Marmar (1996), in this study, 68.4% of the sample of young adults endorsed symptomology consistent with "Partial PTSD" or "Probable PTSD" related to a food-induced allergic reaction over the past year (see Figure 11). This statistic was higher than that seen in larger-scale studies, where 41.4% of participants met criteria for probable or partial PTSD following anaphylaxis as defined by scores on the IES-R-Korean Version (Lee et al., 2020), and 55% participants met criteria for probable

or partial PTSD following anaphylaxis as defined by scores on the Post Traumatic Stress Disorder Checklist (Chung et al., 2011).

Participants in this study endorsed symptoms associated with all four symptom categories described in PTSD: Intrusion, avoidance, hyperarousal, and negative alterations in mood/cognition (APA, 2022). The presence of PTSS was described as exacerbating the underlying psychosocial burdens of FA management. Participants noted that PTSS led them to engage in excessive safety behaviors beyond what they understood to be medically necessary. As a result, participants reported that they did not participate in their preferred activities/hobbies, and missed out on social engagements with friends/family. These themes were consistent with the FA literature on hypervigilance and the use of avoidance-focused coping strategies post-anaphylaxis (Chung et al., 2011).

Notably, participants sought out new forms of FA medications that were thought to reduce some of the burden associated with allergic disease management, including Xolair<sup>TM</sup> and Neffy<sup>TM</sup>. There was some evidence that participants were preemptively utilizing medical interventions/treatments and/or seeking emergency services when they struggled to determine the origin of their acute reaction symptoms. This finding was reflective of the literature on emergency department overutilization for anxiety and/or panic attacks (Dark et al., 2017). While allergy/immunology physicians encourage emergency treatment of anaphylaxis – hence the slogan, "Epi First, Epi Fast" – this approach may be associated with significant financial and psychosocial costs to those routinely struggling to differentiate between anxiety and anaphylaxis.

Participants recognized the value of mental health treatment for addressing food-allergy related distress. Nearly all of the participants who reported that they received mental health care for a condition related to their FA found the intervention to be beneficial, and of those who had

never discussed FA management with a mental health provider, 44% believed they would benefit from doing so (see Interview Findings). Despite this, participants in this study highlighted the lack of mental health clinicians trained to treat this population, corroborating the recent findings of the Global Access to Psychology Services (GAPS) for Food Allergy study that found that there are few mental health providers that A/Is can refer their patients to (Knibb et al., 2024). The awareness of a lack of professional and community resources exacerbated the overall sense of isolation associated with allergic disease management for the participants.

# **Subquestions**

To capture the universal essence of this phenomenon, the study was further grounded in two subquestions: (1) What is the collective experience of food-allergic young adults in attempting to distinguish anxiety symptoms from anaphylaxis symptoms, and (2) how do food-allergic young adults attempt to distinguish anxiety symptoms from anaphylaxis symptoms, and is it effective?

Question One: What is the Collective Experience of Food-Allergic Young Adults in Attempting to Distinguish Anxiety Symptoms from Anaphylaxis Symptoms?

The results of this study supported the hypothesis that there is a shared lived experience among food-allergic young adults in attempting to differentiate anxiety symptoms from anaphylaxis symptoms. Echoing the emerging literature regarding the difficulty of distinguishing the two acute reactions, 65% of the sample reported that sometimes they cannot tell the difference between anxiety and anaphylaxis (see Figure 10). Overarching themes emerged across their experiences. Participants endorsed an overwhelming sense of anxiety while trying to determine the origin of their symptoms. The overlapping symptomology made it increasingly difficult for those in this study to determine if the sensations were anxiety-based, the beginning

of a life-threatening allergic reaction, or a combination of both. Common physiological sensations experienced during the phenomenon included: Shortness of breath, difficulty swallowing, GI distress, increased heart rate, and hot flashes. Of note, participants were particularly sensitive to any homeostatic change to the mouth, lips, or throat – offering further evidence of the role of interoception in fear learning and PTSD in the theory posed by Joshi, Aupperle, and Khalsa (2023). There were also distinct patterns of thinking across the participants during this phenomenon. They described that cognitions emerged in response to the physiological disturbances and were also the impetus for physiological disturbances. They reported a tendency to catastrophize, jump to conclusions, and predict worst-case scenarios. The panic-driven thinking negatively impacted their ability to appropriately respond and/or think critically during the phenomenon. The participants also tended to behave in predictable ways. Many laid out their personal emergency medications so that they were readily available if needed. As a precaution, several participants even headed towards the nearest emergency room or preemptively utilized their emergency medications. There was a shared sentiment across participants that it was "better to be safe than sorry" in these situations. Regardless of the origin of their symptoms, the experience was mentally, emotionally, and physically exhausting for the participants. They experienced fatigue and significant disruption to their day-to-day functioning, even if the acute reaction did not ultimately require further medical intervention.

Several contextual factors influenced the collective experience of the participants while attempting to distinguish anxiety symptoms from anaphylaxis symptoms. The perceived access to rescue medications, emergency department services, and social supports played a role in the experience of the phenomenon. Baseline stress levels made it more likely for participants to have a psychogenic reaction, made it more difficult to differentiate between anxiety and anaphylaxis,

and increased the severity of anxiety symptoms while attempting to authenticate anaphylaxis symptoms.

Question Two: How do Food-Allergic Young Adults Attempt to Distinguish Anxiety Symptoms from Anaphylaxis Symptoms, and Is It Effective?

Participants had some strategies for differentiating their symptoms during the initial five to ten minutes of the acute reaction. They relied on physiological cues and consultation in the early stages of symptoms. Notably, one of the key differentiators was passive timekeeping, given that anaphylaxis symptoms were thought to naturally escalate with time, while anxiety symptoms would naturally dissipate with time. The amount of time needed to pass, without an escalation of symptoms, to confirm that the acute reaction was anxiety-based ranged from 15 to 30 minutes from the time the food was ingested. Stress reduction techniques were especially valuable during this time to help keep the participant comfortable while monitoring symptom progression. While some of the tools were considered by the participants to be effective, only 20% (n=5) of the sample reported that they can always tell the difference between the two acute reactions (see Figure 9). Further, given that several of the strategies employed by the participants subjected them to prolonged distress before the symptoms could be authenticated by default, labeling them as "effective" could be debated.

#### Limitations

Beyond the methodological limitations discussed in Chapter 3, another limitation of this study is the relatively small, homogenous sample of participants. The utilization of convenience and snowball sampling resulted in a sample that was overwhelmingly White, female, and educated. Despite there being some demographic variability among the thirteen (n=13) participants who completed the Survey Questionnaire and were eligible for the Interview Phase

of this study (see Figure 7), White women represented 80% (n=4) of the sample who volunteered and completed the qualitative interview. The demographic variables of the sample were not representative of the larger population of food-allergic young adults – Most notably in terms of race/ethnicity, socioeconomic status (SES), and risk of health inequities. FA disproportionately impacts Black, Hispanic, and Asian populations compared to non-Hispanic White cohorts, all of which were underrepresented in this sample. Further, epidemiological research suggests that individuals of lower socioeconomic status (SES) are more likely to have FAs (Jiang et al., 2023). Yet, this sample represented a highly educated subset of the FA community with adequate access to specialty medical care, who had the means to receive a proper diagnosis and seek emergency medical care. Therefore, the findings from the study cannot be generalized beyond the sample of participants in this study.

# **Clinical Implications**

The findings of this study underscore the critical need for expanded research and education efforts into the psychosocial dimensions of allergic disease management. The participants in this study echoed the well-documented impact of FAs on mental health by articulating their shared experiences of anxiety and anaphylaxis. The collective meaning of differentiating between the two acute reactions has clinical relevance for both medical and mental health professionals. For example, this phenomenon has informed the practice of the Division of Allergy and Immunology at the National Children's Health Care System in Washington, D.C. The misinterpretation of anxiety symptoms as an allergic reaction – on behalf of the patient or the provider – can lead A/Is to prematurely discontinue an oral food challenge. To prevent this, the clinic has started including mental health professionals in the exam room during an oral food challenge. Not only does this serve to support the patient and their family

during the appointment, but it may help A/I providers improve diagnostic clarity and avoid prescribing unnecessary avoidance of that food.

These findings of this study can also be used as further justification of the growing need for public health initiatives that bridge the treatment gap across the FA population. The systemic factors that put low income communities and persons of color at increased risk of poor health outcomes are evident in FA (Cook, Argenio, & Lovinsky-Desir, 2021). This research highlights the pitfalls of the A/I, emergency medicine, primary care, and psychology fields in addressing the overall concerns of the subset of the FA community with the *most* access to resources. If the White, educated, and high-SES demographic represented in this study's sample is experiencing such significant barriers to treatment, it is likely that the populations most at risk for health inequities are facing even greater challenges.

This study has amplified the voices of those who have endured the lasting effects of anaphylaxis. The participant narratives are a powerful testament to the psychosocial burdens of FA management. The constructed essence of 'Anxiety or Anaphylaxis?' may serve as a sense of validation, community, and support to those navigating the often overlooked psychological aspects of allergic disease. Notably, the findings of this research draw warranted attention to the distinct needs of this subset of the young-adult FA population. With the majority of FA resources directed towards pediatric patients and their caregivers, this research addresses the gaps in care across the lifespan.

## **Future Directions**

#### **For Continued Research**

Although beyond the scope of this dissertation, a more robust assessment of PTSS in participants is warranted. In this study, participants were not required to actively be experiencing

PTSS; rather, the study sought to reflect on the lived experiences of PTSS when they were present sometime over the past twelve months. This timeline kept the IAR within the participant's recent memory, while still offering a wide enough time frame to support sampling goals. To address this limitation, future studies can improve internal validity by narrowing the time frame of the inclusionary criteria. Assessing the relationship between the amount of time elapsed since the IAR and the presence/severity of PTSS could better answer the question of whether symptoms were more representative of acute stress, partial PTSD, or probable PTSD. Similarly, it will be important for future studies to investigate if there were meaningful differences among the subscales on the IES-R. A deeper statistical analysis of the Avoidance, Hyperarousal, and Intrusion symptoms addressed by this measure may have better informed the research question about the functional impacts of PTSS following anaphylaxis.

Future studies should investigate if there are potential risk factors or protective factors for developing PTSS following anaphylaxis. A previous study found that the severity of an anaphylactic allergic reaction was not predictive of the development of PTSD (Lee et al., 2020). It will be valuable for medical and mental health providers alike to be able to identify any factors (e.g., number of allergic reactions, perceived access to resources) that put their patients at higher risk for developing PTSS. Early intervention strategies and/or preventative measures could help mitigate the risk of developing PTSS following an allergic reaction in those patients.

In the aftermath of a severe allergic reaction, the participants in this study sought out new forms of FA medications that were thought to reduce some of the burden associated with allergic disease management. With the recent FDA approvals of Neffy<sup>TM</sup> and Xolair<sup>TM</sup>, continued research should formally investigate the hypothesized impact of those medications on reducing FA anxiety.

#### **In Clinical Practice**

Given that 11% of adults and 8% of children in the United States have a FA, it is quite likely that mental health providers will encounter a patient with FA at some point throughout their careers (Warren, Jiang, & Gupta, 2020). Consequently, mental health providers need to be better informed about the psychological impacts of allergic disease. It will be important for mental health professionals to have a foundational understanding of the relationship between FA avoidance and quality of life (see Figure 1). Consultation with A/I will be essential for determining the level of FA-related anxiety that is adaptive, without fostering hypervigilance and over-avoidance beyond what is medically necessary. Clinicians should also be educated on the prominent psychosocial concerns faced by this community, including bullying, body image disturbance, and disordered eating behaviors.

In order to best meet the needs of their patients, mental health providers require tools that can help effectively screen, diagnose, and treat FA-related distress. An expansion of the Scale for Food Allergy Anxiety (SOFAA) (Dahlsgaard et al., 2022) to include adult cohorts could help better address the needs of the FA patient population across the lifespan. Similar to the protocols proposed by Dahlsgaard, Lewis, and Spergel (2023) and Taylor and Lewis (2018), more evidence-based treatment manuals should be adapted for use within the FA community. Further, the Academy for Food Allergy Counseling (AFAC) provides educational and networking opportunities to licensed professionals interested in improving their competency levels in this area of practice. This may be an effective avenue for distributing FA resources to mental health providers as they are developed. As the mental health field continues to make strides in increasing the number of FA-informed mental health providers available to patients, A/I will be better equipped to provide appropriate referral sources to their patients, when indicated.

Given that 67.7% of adults and 77.2% of caregivers reported psychological distress related to their or their child's food allergy, education on the psychosocial burdens of allergic disease management should be a permanent fixture of A/I curriculum and training (Knibb et al., 2024). Both preventative and reactionary intervention strategies should be employed during A/I appointments. In a global patient survey, less than 20% of patients were screened for FA-related psychological distress during their allergy/immunology appointment (Knibb et al., 2024). The implementation of a brief patient or caregiver survey of FA-related distress during routine care appointments can help providers identify patients in need of further intervention – Especially before an OFC or following a severe allergic reaction. Allergists and primary care doctors should also be prepared to routinely discuss FA mental health concerns with their patients. FA-informed health psychologists and behavioral medicine specialists can educate physicians on how to best discuss these concerns with their patients through psychoeducation resources, consultation, and preceptorship opportunities.

### Conclusion

It is the hope that a greater understanding of anaphylaxis as a medical trauma will inspire generations of health professionals to raise awareness about the psychosocial ramifications of allergic disease management. Although the results of this study cannot be generalized beyond the sample of participants, the findings underscore the importance of stronger interdisciplinary collaboration between medical and mental health professionals. Integrated care teams can bridge the gap between physical and psychological care needs by increasing professional consultation and collaboration. Multidisciplinary practice has the potential to streamline treatment, improve clinical outcomes, and alleviate undue psychosocial burden across this growing patient population. Future research should continue to explore risk factors and tailored protocols that can

reduce FA-related distress and improve treatment outcomes across diverse communities. By amplifying FA voices and fostering stronger interdisciplinary collaboration, we can pave the way towards mitigating undue psychosocial burden across this community.

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# Appendix A

# **Impact of Event Scale - Revised**

#### **IMPACT OF EVENT SCALE-REVISED**

## Daniel S. Weiss, PhD & Charles R. Marmar, MD

Instructions: Below is a list of difficulties people sometimes have after stressful life events.

Please read each item and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to\_\_\_\_\_\_, how much were you distressed or bothered by these difficulties?

Not at all=0, Little bit =1, Moderately=2, Quite a bit = 3, Extremely= 4

Sr.No	Statement	0	1	2	3	4
1.	Any reminder brought back feelings about it					
2.	I had trouble staying asleep.					
3.	Other things kept making me think about it.					
4.	I felt irritable and angry.					
5.	I avoided letting myself get upset when I thought about it or was					
	reminded of it.					
6.	I thought about it when I didn't mean to					
7.	I felt as if it hadn't happened or wasn't real					
8.	I stayed away from reminders about it.					
9.	Pictures about it popped into my mind.					
10	I was jumpy and easily startled.					
11	I tried not to think about it.					
12	I was aware that I still had a lot of feelings about it, but I didn't deal with					
	them.					
13	My feelings about it were kind of numb.					
14	I found myself acting or feeling like I was back at that time.					
15	I had trouble falling asleep.					
16	I had waves of strong feelings about it.					
17	I tried to remove it from my memory.					
18	I had trouble concentrating.					
19	Reminders of it caused me to have physical reactions, such as sweating,					
	trouble breathing.					
20	I had dreams about it.					
21	I felt watchful and on-guard.					
22	I tried not to talk about it.					

Avoidance Subscale = mean of items 5, 7, 8, 11, 12, 13, 17, 22

Intrusion Subscale = mean of items 1, 2, 3, 6, 9, 16, 20

Hyper arousal Subscale = mean of items 4, 10, 14, 15, 18, 19, 21

Note: The IES-R is not a diagnostic or screening tool for PTSD; rather, it relies on a patient's own report of symptoms and is used to gauge response no sooner than two weeks after a traumatic event, as well as to evaluate recovery.

# Appendix B

# **Screening Questionnaire**

Age:
Have you been diagnosed with an IgE-mediated food allergy?  • Yes • No
<b>Anaphylaxis:</b> For the purposes of this study, anaphylaxis is a type of severe allergic reaction in response to foods, insects, medications, or latex. Symptoms of anaphylaxis include hives, swelling, difficulty swallowing, shortness of breath, nausea, vomiting, diarrhea, changes in blood pressure, rapid heart rate, and/or feeling dizzy.
<b>Medical Intervention:</b> For the purposes of this study, medical intervention includes: Use of an epinephrine auto injector (e.g., EpiPen, Auvi-Q), an emergency medical screening (e.g., emergency room, urgent care, 911), and/or the prescription of rescue medications from your doctor (e.g., steroids).
What is the month and year of your most recent food-induced anaphylactic allergic reaction resulting in medical intervention?

## **Appendix C**

Survey
What gender do you identify as?
What race or ethnicity do you identify as?
<ul> <li>What is your highest education level? Select one.</li> <li>Less Than High School</li> <li>High School Diploma or Equivalent (GED)</li> <li>Associates (AS, AAS)</li> <li>Undergraduate (BA, BS)</li> <li>Masters (MA, MS)</li> <li>Doctorate (MD, PhD)</li> <li>Not Listed (specify):</li> </ul>
Which of the following physician-diagnosed, IgE-mediated food allergies do you manage?  Select all that apply.  Peanut  Tree Nuts  Wheat  Milk  Soy  Egg

• Not Listed (specify): \_\_\_\_

Which of the following related medical conditions do you manage? Select all that apply.

• Asthma

ShellfishFinfishSesame

- Allergic Rhinitis
- Atopic Dermatitis (Eczema)
- Chronic Urticaria
- Eosinophilic Gastrointestinal Diseases (EGIDs)
- Food Protein-Induced Enterocolitis Syndrome (FPIES)
- Food Protein-Induced Allergic Proctocolitis (FPIAP)
- Oral Allergy Syndrome (OAS)
- Not Listed (specify): \_\_\_\_\_

**Anaphylaxis:** For the purposes of this study, anaphylaxis is a type of severe allergic reaction in response to foods, insects, medications, or latex. Symptoms of anaphylaxis include hives, swelling,

difficulty swallowing, shortness of breath, nausea, vomiting, diarrhea, changes in blood pressure, rapid heart rate, and/or feeling dizzy.

**Medical Intervention:** For the purposes of this study, medical intervention includes: Use of an epinephrine auto injector (e.g., EpiPen, Auvi-Q), an emergency medical screening (e.g., emergency room, urgent care, 911), and/or the prescription of rescue medications from your doctor (e.g., steroids).

Lifetime number of food-induced anaphylactic allergic reactions resulting in medical intervention?

- 0
- 1
- 2
- 3+

Have you ever experienced a food-induced anaphylactic allergic reaction, but did **not** seek medical intervention due to cost, health insurance coverage, distance to care, or another reason that made it hard for you to access care?

- No
- Yes
   If yes, please describe: \_\_\_\_.

Have you ever experienced a food-induced anaphylactic allergic reaction, but did **not** seek medical intervention for another reason that is not included above (e.g., I did not think I needed medical care, time constraints, social pressures)?

- No
- Yes If yes, please describe: \_\_\_\_.

**Mental Health Treatment:** People seek care for their psychological health for many reasons, and mental health treatment can look different for everyone. For the purposes of this study, Mental Health Treatment includes: (1) Therapy, and (2) Psychiatric Medication Management.

- 1. **Therapy:** For the purposes of this study, therapy <u>includes</u>: Individual or group counseling, college counseling center, partial hospitalization or hospitalization program, or behavioral medicine treatment.
- 2. **Psychiatric Medication Management:** For the purposes of this study, psychiatric medication management <u>includes</u>: Prescription medication prescribed by a healthcare professional (e.g., Primary Care Doctor, Psychiatrist, Nurse Practitioner) for the purpose of treating mental health concerns.

Which of the following statements best describes you? Select all that apply.

- I have never engaged in any form of mental health treatment.
- I have engaged in a form of therapy.
- I have engaged in a form of psychiatric medication management.
- Does not apply.
- Prefer not to answer.

Which of the following statements best describes you? Select all that apply.

- I have never engaged in any form of mental health treatment.
- I have engaged in a form of mental health treatment for a condition *unrelated* to my food allergies.
- I have engaged in a form of mental health treatment for a condition *unrelated* to food allergies, but did end up discussing food allergies with my provider.
- I have engaged in a form of mental health treatment for a condition *related* to my food allergies.
- Does not apply.
- Prefer not to answer.

Which of the following statements best describes you? Select all that apply.

- I do not think I *would* benefit from mental health treatment.
- I do not think I *have* benefitted from mental health treatment.
- I think I would benefit from mental health treatment *unrelated* to my food allergies.
- I think I would benefit from mental health treatment *related* to my food allergies.
- Does not apply.
- Prefer not to answer.

How much do you believe y	our food allergies have an effect of	on your mental health?
(0)	(5)	(10)
No Effect	Moderate Effect	Significant Effect

Which of the following statements best describes you? Select one.

- Sometimes I can't tell the difference between allergic reactions and anxiety.
- I can almost always tell the difference between allergic reactions and anxiety.
- I rarely experience anxiety.
- I have had too few reactions to tell.
- Prefer not to answer.

Have you ever been diagnosed with any anxiety or anxiety-related disorder (e.g., Generalized Anxiety, Panic Disorder, PTSD, Acute Stress Disorder)?

- Yes
- No
- I don't know.
- Prefer not to answer.

Please provide any additional information that you would like the research team to know about your experience with food allergies and/or mental health: \_\_\_\_\_.

## Appendix D

#### Resources

Thank you for your interest in this research study. Below are several relevant resources related to food allergies and mental health that you may find useful.

Food Allergy Research and Education (FARE) is a resource providing general food allergy education for patients and families.

#### **FARE**

Food Allergy Research and Education https://www.foodallergy.org/

Food allergy can have an impact on mental health. The Food Allergy Counselor Directory offers further information about the intersectionality between mental health and food allergies, and connects food allergy patients and families with licensed mental health professionals.

# **The Food Allergy Counselor Directory**

Allergy mental health directory, resources, and tools.

https://www.foodallergycounselor.com/directory

If you or a loved one are seeking individual mental health treatment, Psychology Today connects patients and families with licensed clinicians in their area.

## **Psychology Today**

Find detailed listings for mental health professionals.

https://www.psychologytoday.com/us?tr=Hdr Brand

If you or a loved one are in danger of hurting themselves or others, these crisis hotlines are available for 24/7 assistance via phone call or text message.

#### **Crisis Text Line**

In crisis or need to talk to someone? Text HOME to 741741 to reach a volunteer crisis counselor.

https://www.crisistextline.org/

### 988 Suicide & Crisis Lifeline

The 988 Lifeline Provides 24/7, free and confidential support for people in distress. <a href="https://988lifeline.org/">https://988lifeline.org/</a>

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